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## Feature Story

### NIDCD-Funded Autism Center of Excellence is the First to Study Minimally Verbal Children

By Robin Latham

The past decade has been a time of great advances in research exploring the causes, diagnosis, and treatment of autism spectrum disorder (ASD), a complex developmental disorder that affects behavior, communication, social interaction, and learning. There have also been big improvements in identifying children with ASD, which the Centers for Disease Control and Prevention (CDC) now estimate as affecting 1 in every 88 children in the United States. Better and earlier interventions are helping many children with ASD communicate and interact more successfully with their peers and the rest of the world.

Even with these strides, however, there still remain a number of children with ASD—a group that some experts estimate could be as high as 30 percent—who may never develop functional language skills or learn to speak, in spite of having access to early intervention and intensive therapies. As they grow, these children develop few ways to communicate verbally with others and are cut off from one of the most basic of human needs—self-expression and connection with other people.

To find out more about this little-studied subgroup of children with ASD, the NIDCD recently awarded a grant to Boston University to look more closely at the children's underlying skills and impairments and how the use of creative and carefully targeted interventions could potentially help them develop basic communication skills. The \$10 million grant, awarded over five years, is one of nine Autism Centers of Excellence (ACE) grants awarded by the National Institutes of Health (NIH) in 2012. These grants support research at individual centers or within research networks dedicated to the study of ASD.



Helen Tager-Flusberg, Ph.D.  
Photo credit: Martin Flusberg

The NIDCD grant will allow researchers led by Helen Tager-Flusberg, Ph.D., professor of psychology, to direct an ACE based at Boston University that pulls together other NIDCD-funded researchers from the university, as well as collaborators from Harvard Medical School and Northeastern University, also in Boston, and Albert Einstein College of Medicine, in New York.

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<http://www.nidcd.nih.gov/health/inside/>

“The sad truth is that despite the enormous growth in autism research, these minimally verbal children have been neglected in terms of our research population, primarily because they are so difficult to recruit and study,” says Dr. Tager-Flusberg.

These scientists have expertise in research related to speech, auditory processing, and imaging techniques. The ACE funding gives them the opportunity to collaborate and apply what they know about the acquisition and production of language to better understand these challenged children.

“The sad truth is that despite the enormous growth in autism research, these minimally verbal children have been neglected in terms of our research population, primarily because they are so difficult to recruit and study,” says Dr. Tager-Flusberg. “You can imagine if you’ve gone through 8 to 10 years of life not being able to communicate with other people that it might contribute to challenging behaviors.”

The other challenge for studying minimally verbal children with ASD is one of assessment. How can you use a standard IQ test with children who don’t speak and have limited language skills? A previous supplemental grant from the NIDCD allowed Dr. Tager-Flusberg and her colleagues at Boston University to develop a purely visual test to measure nonverbal skills based on Raven’s Coloured Progressive Matrices, a commonly used test for young children. Administering these and other newly developed nonverbal tests isn’t easy, though.

“For what might be a two-part testing session for some autistic children,” says Dr. Tager-Flusberg, “we have to bring these children in for four to five sessions at least, just to get the same thing accomplished.”

Dr. Tager-Flusberg believes that there are currently teenagers and young adults with ASD who potentially could have been helped to become verbal when they were younger with the right interventions at the right time. “It just requires so much more than they were getting,” Dr. Tager-Flusberg says, “and so it didn’t happen for them.”

This center will be asking some big questions about what makes these children different from other children with ASD. Dr. Tager-Flusberg doesn’t think there is going to be one simple answer, and so the research group will be taking several different approaches to these problems, by using brain imaging techniques to look at auditory processing and the systems and connections involved in initiating and producing speech. They will also be testing a novel intervention that has appeared promising in preliminary studies, and which, if successful, will tell the researchers quite a bit about why these children previously failed to acquire spoken language skills.

“If we don’t address the fundamental research questions about the nature of the problems for these children,” says Dr. Tager-Flusberg, “we’ll never be able to figure out interventions that could help them acquire spoken language.”

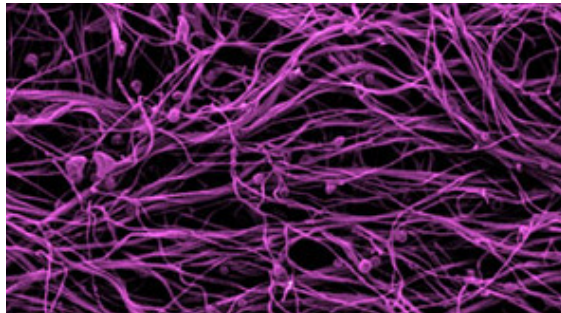
More information about NIDCD supported autism research, go to <http://www.nidcd.nih.gov/funding/programs/vsl/Pages/autism.aspx>.

*The NIH created the ACE program in 2007 to launch an intense and coordinated research program to explore the causes of ASD and find new treatments. To find out more about ACE, go to <http://www.nichd.nih.gov/research/supported/pages/ace.aspx>. In addition to the NIDCD, the NIH institutes that support the ACE program are the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Environmental Health Sciences, the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke. Dr. Tager-Flusberg’s ACE is supported by NIDCD grant P50DC013027.*

## Recent Research and News

### Genetic Technique Restores Sense of Smell in Mice

NIDCD-funded scientists restored the ability to smell in a mouse model of a human genetic disorder that causes congenital anosmia—the inability to smell from birth. The approach used gene therapy to regrow cilia, cell structures that are essential for smell, and which play a key role in a newly recognized class of genetic disorders, known as the ciliopathies. Future studies could begin to plot a way to bring this therapeutic tactic to human study volunteers, which could eventually restore the sense of smell, and a better quality of life, to people who are born with anosmia. To read more, go to <http://www.nidcd.nih.gov/news/releases/12/Pages/090212.aspx>.



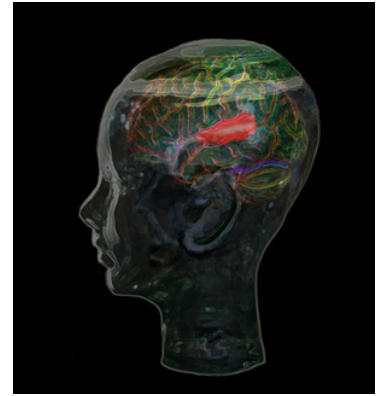
A dense mat of cilia—magnified 1,500 times—stretches across the surface of the olfactory epithelium, the tissue in the nose involved in the sense of smell.

*Credit: University of Michigan*

### The Deaf Brain Processes Touch Differently

People who are born deaf process the sense of touch differently than people who are born with normal hearing, according to research funded by the NIDCD. The finding reveals how the early loss of a sense – in this case hearing – affects brain development. The researchers used a unique apparatus that could deliver soundless puffs of air to the face and visual stimuli in the form of a brief burst of light, and then measured brain activity

using magnetic resonance imaging. The results showed that deaf people use the auditory cortex to process touch stimuli and visual stimuli to a much greater degree than occurs in hearing people. The finding suggests that since the developing auditory cortex of profoundly deaf people isn't exposed to sound stimuli, it adapts and takes on additional sensory processing tasks. To read more, go to <http://www.nidcd.nih.gov/news/releases/12/Pages/071012.aspx>.



This graphic of a human brain is derived from multiple structural magnetic resonance images. At center is the superior temporal region, which contains the human auditory cortex. *Image credit: Christina Karns*

### Children Exposed to HIV in the Womb at Increased Risk for Hearing Loss

Children exposed to HIV in the womb may be more likely to experience hearing loss by age 16 than are their unexposed peers, according to scientists in a National Institutes of Health research network, funded in part by the NIDCD. The researchers estimated that hearing loss affects 9 to 15 percent of HIV-infected children and 5 to 8 percent of children who did not have HIV at birth but whose mothers had HIV infection during pregnancy. The findings suggest that healthcare providers who care for children who have been exposed to HIV in the womb should be aware of the risks for hearing loss in these children and be able to suggest appropriate interventions. To read more about the study and its findings, go to <http://www.nih.gov/news/health/jun2012/nichd-20.htm>.

## NIDCD Highlights

### ASHA Staff Visit NIDCD Labs

Scientists from the NIDCD hosted staff from the national headquarters of the American Speech-Hearing-Language Association (ASHA) in September for a tour of the laboratories of some of the NIDCD's intramural (staff) researchers. ASHA attendees, including the organization's chief executive officer Arlene Pientranton, were welcomed by the NIDCD director, James F. Battey Jr., M.D., Ph.D. Presentations included an overview of the NIDCD, its mission areas, and its public outreach initiatives. ASHA staff then visited two different NIDCD laboratories where they were able to see, hear, and discuss the research of scientists studying hereditary deafness and sensory cell development in the inner ear.



Visitors from ASHA, including the organization's chief executive officer, Arlene Pientranton (pictured, far left, second row from bottom), pose on the steps of the NIDCD's intramural research facility in Gaithersburg, Md., with NIDCD scientists and administrators. The visitors were welcomed by the NIDCD director, James F. Battey Jr., M.D., Ph.D. (not pictured).

### It's a Noisy Planet. On Jeopardy!

Viewers learned about the importance of protecting their hearing during a special Kids Week episode of *Jeopardy!* that broadcast on July 30, 2012. The episode featured the NIDCD *It's a Noisy Planet. Protect Their Hearing*® campaign.



Screen capture courtesy of Jeopardy!

After the show aired, visits to the *Noisy Planet* website more than doubled, and many new followers "liked" the *Noisy Planet* Facebook page. The campaign teaches parents and tweens (children ages 8-12) about healthy hearing habits to protect them from noise-induced hearing loss, which is cumulative, permanent, and preventable.

\*The answer to the *Jeopardy!* question shown above is "What are decibels?"

## Kaye, Perkell Join NDCD Advisory Council

The National Deafness and Other Communication Disorders (NDCD) Advisory Council announces the appointment of two new members. The NDCD Advisory Council advises the U.S. Health and Human Services Secretary, the National Institutes of Health's director, and the NIDCD's director on matters relating to the conduct and support of research and research training, health information dissemination, and other programs.

### Joan Kaye

Ms. Kaye is the executive director of Sophie SoundCheck, a non-profit organization founded by her daughter to raise awareness of the causes and prevention of noise-induced hearing loss. The organization has sponsored workshops, school assembly programs, and fundraiser events nationwide. She has also collaborated with the Starkey Hearing Foundation, the United Nations' Year of the Girl, and the Turkcell program, which supports education for girls with hearing impairments in rural Turkey.

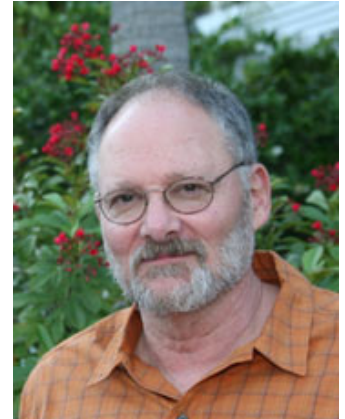
### Joseph Perkell, D.M.D., Ph.D.

Dr. Perkell recently retired as senior research scientist at the Research Laboratory of Electronics at the Massachusetts Institute of Technology (MIT) and the MIT department of brain and cognitive sciences. He also held an appointment as an adjunct professor in the department of cognitive and neural systems at Boston University. His area of research expertise is control and coordination of the movements involved in speech articulation. He is a member of the Acoustical Society of America, the American Speech-Hearing-Language Association, Sigma Xi, and the Society for Neuroscience.

## In Memoriam: Barry Davis, Ph.D.

### Director of the NIDCD Taste and Smell Program

Barry Davis, Ph.D., passed away on July 3, 2012, after a valiant fight against illness. Born on July 24, 1946, in San Pedro, California, Dr. Davis completed his B.A. in psychology at Miami University, Oxford, Ohio in 1968 and his Ph.D. in neuroscience at the University of Rochester Medical School in 1975.



Barry Davis, Ph.D.  
Photo credit: AChemS

Dr. Davis worked in academics for several years as an associate professor then, in 1999, joined the NIDCD as director of the Taste and Smell Program. While at the NIH, his research interests included the anatomical, physiological, and biochemical similarities and differences among brain structures involved in the processing of taste and smell. As a program director, Dr. Davis's broad understanding of the field helped move the NIDCD forward in innovative and productive ways. On a personal level, as many of the grantees who worked with him would attest, Dr. Davis was revered for his fairness, honesty, and direct and candid style. Dr. Davis is survived by his son, Kyle Tucker-Davis, who is a recent graduate of the U.S. Naval Academy.

## Meetings of Interest

### The Association for Research in Otolaryngology

**ARO 36th MidWinter Meeting**  
February 16-20, 2013, Baltimore, Md.

Web info: <http://www.aro.org/mwm/mwm.html>



The Association for Research in Otolaryngology's annual meeting brings together an international group of scientists and physicians dedicated to scientific exploration among all of the disciplines in the field of otolaryngology, involving the ear, nose, head, neck, and related functions including hearing, balance, speech, taste, and smell among others.

### National Hearing Conservation Association NHCA 38th Annual Hearing Conservation Conference

February 21-23, 2013, St. Petersburg, Fla.

Web info: <http://www.hearingconservation.org/displaycommon.cfm?an=6>



Experts will provide an international perspective on the latest research on hearing loss prevention, public and personal health issues related to noise exposure and hearing loss, recent public health and military initiatives for hearing loss prevention, and new and upcoming legislation and recommendations.

### American Academy of Audiology

**Audiology Now! 2013**  
April 3-6, 2013, Anaheim, Calif.

Web info: <http://www.audiologynow.org/>



The annual meeting of the American Academy of Audiology allows practitioners, researchers, and exhibitors to share the latest in clinical concepts, technology, and practice development.

### American Hearing Research Foundation AHRF Symposium on Dizziness and Balance Disorders

April 6, 2013, Oakbrook Terrace, Ill.

Web info: <http://american-hearing.org/>

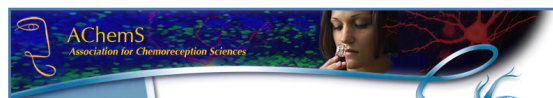


The American Hearing Research Foundation (AHRF) invites patients and health care providers to a free symposium discussing dizziness and balance disorders. Pre-register by calling (312) 726-9670.

### Association for Chemoreception Sciences

**AChemS 2013**  
April 17-20, 2013, Huntington Beach, Calif.

Web info: <http://www.achems.org/i4a/pages/index.cfm?pageid=3962>



The AChemS Annual Meeting brings together researchers from the United States and around the world to present and discuss the latest research in the broad field of the chemical senses, including the senses of taste and smell.

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## National Hispanic Medical Association

### NHMA 17th Annual Conference

April 25-28, 2013, Washington, D.C.

Web info: <http://www.nhmamd.org/index.php/events/17th-annual-conference>

At the National Hispanic Medical Association's annual meeting, physicians, residents, medical students, nurses, dentists, policymakers, health care industry representatives, and partners from the federal and state governments and private sector share their experiences in improving health care delivery for Hispanic populations.



## Beyond the NIDCD

### AHRF Symposium on Dizziness and Balance Disorders

The American Hearing Research Foundation (AHRF) invites patients and health care providers to a free Symposium on Dizziness and Balance Disorders. You can learn about dizziness and the vestibular system, tests and diagnosis, therapies, and potential new treatments for balance disorders. Breakfast and lunch sessions will feature Q&A discussions. Space is limited. Pre-register by calling (312) 726-9670 or go to the AHRF website at <http://american-hearing.org/ahref-news/dizziness-balance-disorders-symposium/>. Registration opens in January 2013.

WHEN: Saturday, April 6, 2013, 7:45a.m.–5 p.m.

WHERE: Hilton Suites Chicago, Oakbrook Terrace, Ill.

### VEDA Website Launches New Patient-Oriented Tools

The Vestibular Disorders Association (VEDA) added new tools to its website, including a downloadable patient medical history form

customized for vestibular patients, and V-PALS—a program that connects members who wish to correspond directly with others who suffer from a vestibular disorder. For more information, go to the VEDA website at <http://vestibular.org/>, email [info@vestibular.org](mailto:info@vestibular.org), or call (800) 837-8428. You can download the patient form on the VEDA website at [https://vestibular.org/sites/default/files/page\\_files/VEDA%20Patient%20Medical%20History%20Form\\_long.pdf](https://vestibular.org/sites/default/files/page_files/VEDA%20Patient%20Medical%20History%20Form_long.pdf).

### Hands & Voices Now Hosts DeafEd.net

An award from the University of New Orleans and Michigan State University to Hands & Voices helped the organization take ownership of Deafed.net, the largest single source of information on the Internet about deaf education. The site has a new look, but the same goal—to enhance collaborative efforts among parents and professionals as they share knowledge and find solutions to improve the social, linguistic, academic, and post-secondary learning opportunities for children who are deaf or hard of hearing. Learn more about DeafEd.net by visiting the website at <http://www.deafed.net/>.

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## New Publication on Maltreatment of Children with Disabilities

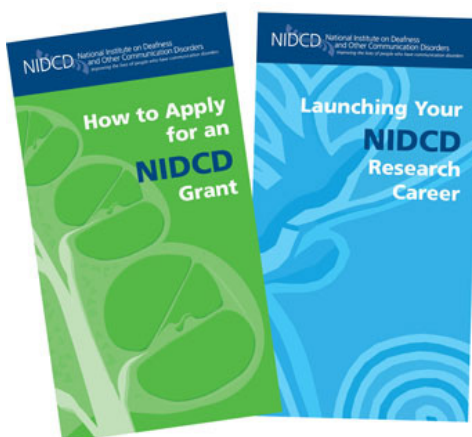
The Child Welfare Information Gateway (a service of HHS) offers an information bulletin for child welfare professionals—The Risk and Prevention

of Maltreatment of Children with Disabilities. The bulletin describes the scope of the problem, its risk factors, and strategies for prevention. Access the bulletin online at <https://www.childwelfare.gov/pubs/prevenres/focus/focus.pdf>.

## New Resources

### Publications for Researchers Now Available on the NIDCD Website

Two publications for biomedical researchers early in their careers have been updated on the NIDCD website. *How to Apply for an NIDCD Grant*, which offers guidance and suggestions for successfully applying for funding, is available on the NIDCD website at <http://www.nidcd.nih.gov/funding/Pages/How-to-Apply-for-an-NIDCD-Grant.aspx>. *Launching Your NIDCD Research Career*, which offers guidance and information about funding opportunities from the NIDCD, is available on the NIDCD website at <http://www.nidcd.nih.gov/research/Pages/Launching-Your-NIDCD-Research-Career.aspx>.



Print copies are available from the NIDCD Information Clearinghouse by using the online ordering form at [https://www.nidcd.nih.gov/order/pubs\\_title.aspx?type=general](https://www.nidcd.nih.gov/order/pubs_title.aspx?type=general).

### Epidemiological Charts and Tables Now Online

The NIDCD website offers eight new or updated charts and tables that present epidemiological statistics on topics related to hearing and ear infections. Quickly find out trends in ear infection diagnosis, hearing aid usage statistics, and the rates of newborn hearing screening across the country over the past decade. Visit the updated charts and tables on the NIDCD website at <http://www.nidcd.nih.gov/health/statistics/Pages/charts.aspx>.

*Inside* is produced by the Office of Health Communication and Public Liaison, NIDCD. The material in this newsletter is not copyrighted, and we encourage its use or reprinting. For more information about this newsletter, please contact the editors, Robert Miranda-Acevedo at [miranda1@nidcd.nih.gov](mailto:miranda1@nidcd.nih.gov) or Robin Latham at [robin.latham@nih.gov](mailto:robin.latham@nih.gov).

For general health information about communication disorders, contact the NIDCD Information Clearinghouse at:  
**Voice: (800) 241-1044**  
**TTY: (800) 241-1055**  
**E-mail: [nidcdinfo@nidcd.nih.gov](mailto:nidcdinfo@nidcd.nih.gov)**