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COSSA Washington Update

IN THIS ISSUE:

- [Congress Ready to Move Federal Spending Legislation](#)
- [45 Years of NICHD Research Progress on Intellectual And Developmental Disabilities Celebrated on Capitol Hill](#)
- [Genome's Francis Collins To Step Down; Guttmacher To Be Acting Director](#)
- [NSF's SRS Division Re-Examines Confidentiality And Privacy](#)
- [2ND Conference on Interventions to Encourage Minorities to Pursue Research Careers](#)
- [The Condition of Education 2008 Report Released](#)
- [National Advisory Panel Calls for More Research on Math Teaching and Learning](#)
- [Congressional Briefing Examines Lack of Geriatric Care for an Increasing Elderly Population](#)
- [NIH Expands CTSA Consortium](#)
- [Web Discussion of NIH Research, Condition, and Disease Categorization Planned for June 11](#)
- [NIH, AHRQ to Hold 2008 Diabetes and Obesity Disparities In Healthcare Systems Conference](#)
- [Editors Note: Correction](#)

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CONGRESS READY TO MOVE ON FEDERAL SPENDING LEGISLATION

Congress returns from its Memorial Day recess ready to complete work on the FY 2008 War Supplemental and the FY 2009 Budget Resolution. This will then allow the Appropriations Subcommittees to begin marking up their FY 2009 bills for the individual agencies. How far that process will go is still uncertain.

On May 22, the Senate adopted its version of the FY 2008 War Supplemental. Unlike the House version, it includes funds for the wars in Iraq and Afghanistan and does not include restrictions on how those wars are conducted. The Senate version also includes \$1.2 billion for science agencies, allotting \$400 million for the National Institutes of Health and \$200 million for the National Science Foundation. Both the House and Senate versions have funding for the Census Bureau to help fix the problems created by the move from handheld computers to paper for the Non-Response Follow Up planning activities (see Update [April 21, 2008](#)).

The bill, H.R. 2642, now returns to the House, which expects to consider it on June 6. President Bush has threatened to veto the bill for its excessive domestic spending and the House-approved policy advice on the wars. The House leadership has voiced its desire to come up with a bill that the President will sign.

The House and Senate have also agreed on a FY 2009 Budget Resolution (S.Con.Res. 70) and should complete action on it the week of June 2. The resolution sets the parameters for consideration by the Appropriations' Committees of the FY 2009 funding for the agencies and programs. The President does not sign or veto the resolution. The final budget would exceed President Bush's proposed FY 2009 limit on discretionary spending by \$24.5 billion. If the appropriations process concludes with Bush still in office, "a big if" according to many in Congress, this would lead to another confrontation over spending and more vetoes.

The resolution includes report language that suggests there is enough money provided to support the goals of the America COMPETES Act, which includes doubling the National Science Foundation's budget in seven years. There is also an assumption that the National Institutes of Health will receive appropriations above the President's level request for FY 2009.

45 YEARS OF NICHD RESEARCH PROGRESS ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES CELEBRATED ON CAPITOL HILL



Duane Alexander

On May 22, the Friends of NICHD sponsored a congressional briefing to celebrate 45 years of research accomplishments by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Twenty-two organizations, including COSSA, the American Educational Research Association, the American Psychological Association, and Society for Research in Child Development sponsored the event which highlighted the work of the NICHD's Intellectual and Developmental Disabilities Research Centers. The [Friends of NICHD](#) is an independent coalition of more than 100 organizations that supports NICHD's mission. Member organizations represent scientists, physicians, health care providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities.

Briefing speakers included Duane Alexander, Director, NICHD; Pat Levitt, Vanderbilt University; Steven F. Warren, University of Kansas; Marsha Mailick Seltzer, University of Wisconsin-Madison; and Jana Monaco, Family Faculty Member for Children's National Medical Center.

NICHD Director Duane Alexander noted that it was his first appearance on the Hill since the institute's name change, which was appropriate given the topic. In appreciation of the congressionally-mandated name change for the Institute, Alexander reflected on NICHD's history. He explained that at the time of the creation of the Institute, there were six million people with developmental disabilities who were institutionalized or received custodial care, essentially shut off from society. Mildly retard individuals, he observed, lived at home and had "a limited existence." Research was done in the institutions and third-rate publications were published in obscure journals. Two people, according to the NICHD director, were responsible for changing this, Robert E. Cook (The Johns Hopkins University) and Eunice Kennedy Shriver, sister to President John F. Kennedy. Cook was appointed to the Kennedy's transition team for health, education, and welfare. It was a volunteer position.



Levitt, Seltzer, and Warren

Alexander observed that as a result of Cook's and Shriver's successful efforts, in 1963, Congress passed legislation requiring the establishment of "centers of excellence" designed "to bring the research out of the shadows." The Intellectual and Developmental Disabilities Research Centers program was the nation's first sustained and integrated effort to prevent and treat disabilities through biomedical and behavioral research. To commemorate the Centers' anniversary, the IDDRC program was officially renamed in honor of Mrs. Shriver, who worked "tirelessly for their establishment." Today, the IDDRC Association is the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. The centers conduct research into the causes, prevention, and interventions for autism, Down syndrome, Fragile X syndrome, cerebral palsy, and hundreds of other intellectual and developmental disabilities in children and adults.

Recent Discoveries in Autism and Neurodevelopmental Disorders

Levitt discussed the recent discoveries in autism and other neurodevelopmental disorders. He noted that one in five children, according to the Centers for Disease Control and Prevention, are born with a developmental disorder, affecting one out of every two and a half families. He stressed the importance of studying rare disorders. "Discoveries about rare disorders have led the way to new understanding of brain and molecular architecture," he explained. Some of these discoveries have led to strategies to prevent or even reverse clinical syndromes in animal models. The models have some similarities with children with the same genetic disorders. As a result, "in three short years" clinical trials have been initiated in Tuberous Sclerosis, Fragile X, and Rhetts's Syndrome. The research has "changed the way we think about the brain," he pointed out, adding that it also provide possibilities for changing the course of a disorder.

Using autisms, highly heritable disorders that are common, complex and heterogeneous in its core symptoms, as an example, Levitt explained that autisms have "major differences in developmental course." There is also variation in co-occurring conditions (e.g., anxiety, thought disorder, aggression, self-injury, epilepsy, sleep, gastro-intestinal, immune)" with a "wide range in responsiveness to treatments," according to Levitt. He stressed that the "risks for autisms may lie with dozens of genes and environmental factors. Past research has described what autism is not. Current research, he stressed, describes what autism is and emphasizes the examination of small details that allow for a full gene analysis. What is now important is how the condition affects the behavior of the child. Why does one child respond and another one does not, he posited. Genetic studies allow for the identification of unique types of autisms and for better diagnosis and treatments.

'Translation of Basic Research to Individual Impacts'

Warren discussed what he termed the translation of basic research to individual impacts. He stressed that in order to understand problems that occur in development, it is crucial to understand the normal developmental process. Echoing Levitt, Warren emphasized that development is driven by both heredity and environment. He described early intervention as: 1) focused efforts to enhance child development and family functioning during the first three years of life; 2) may start prior to birth; and 3) may involve as little as providing general information to the family and as much as diet modifications, surgery, parent training, and intensive behavioral interventions. The challenges associated with this period, he explained, are that delays and disorders are often not identified until children are two or three years or older, the impact of many interventions are uncertain, and the service system that supports children and families is highly varied across communities and states.

Warren noted further, that the genetic bases of many disorders have been discovered. In addition, newborn screening programs are expanding. He cited as an example programs that screen infant hearing which have resulted in cochlear implants becoming routine.

Other progress that has resulted from the support of NIH research, Warren pointed out, includes the increase of life expectancy of 50 years for individuals with Down syndrome. This is due to the identification of "critical biological and environmental factors that impact early brain development." He concluded by noting that new and improved treatments under consideration and new measurement technologies may soon revolutionize research and treatment.

The Impact of Lifelong Caregiving

Seltzer described her research, a longitudinal study (Adolescents and Adults with Autism: The Impact of Family Caregiving) spanning 12 years and funded by the NIH. It looks at the impact of life-long caregiving, including the daily life of families of adolescents and adults with autism, and how it differs from the norm and how the family environment can affect the symptoms of the individual with autism. Seltzer explained that autism has been shown to be the most stressful of all developmental disorders for the family system. She noted that the risk of a second child with autism is between four and ten percent. Autism is more heritable than schizophrenia or bipolar disorder, Seltzer explained that there is a diversity of family experiences.

The goal of her research is to investigate the course of change in adolescent and adulthood and its impact on the



family. For eight days, study participants receive a telephone call to assess their time use, daily stresses, positive events, mood, and physical health. A comparison group from a nationally-representative sample of non-caregiving mothers is also used. In addition to the daily telephone survey, saliva samples are taken each day to measure the level of the stress hormone cortisol. She explained that cortisol has "a very characteristic pattern of daily expression. In healthy individuals, cortisol rises early in the day to help us 'rev up' for the day's challenges and declines thereafter. At the end of the day, cortisol is very low which allows for adequate rest. Dysregulation of cortisol has been linked to physical and mental health problems, she noted.

Seltzer observed that not only is there an effect of the child's behaviors and symptoms on the mother, her data also suggests that the emotional climate of the family has an effect on the child's behaviors and symptoms. According to Seltzer, "high levels of criticism by parents predict significantly increasing repetitive behaviors in children with autism 18 months later." Conversely, "high levels of warmth by parents predict significantly declining repetitive behaviors 18 months later."

According to Seltzer, recent research has revealed that the lifetime cost of medical and nonmedical care for a person with autism is estimated at \$3.2 million. This sum does not include the impacts on the family - financial, social, and mental and physical health, she stated. Meanwhile, psycho-educational interventions have been shown to reduce criticism and to increase warmth in family members of patients with schizophrenia, Alzheimer's, Parkinson's, and asthma. These interventions have been linked to reduced relapse rates and symptoms. Is there possible application to autism, Seltzer posited. "Although there is evidence that autism is a complex genetic disorder, the reciprocal effects of the family environment on the behavioral phenotype of autism should not be underestimated," she concluded.

A Family's Perspective

Jana Monaco provided a family-view of the toll developmental disorders can cause for a family. Monaco described herself as an "individual with the misfortune of living a 'what if' story." Her children suffer from Isovaleric Acidemia, a rare disorder in which the body is unable to process certain proteins properly. Steven, the oldest, was three when he began exhibiting symptoms of the disease. As a result of his late diagnosis, he suffers from severe brain damage. On the other hand, it was discovered through amniocentesis that her daughter, Caroline, also had the disease, but because of the early diagnosis and research-based interventions, Caroline is developing as a normal child.

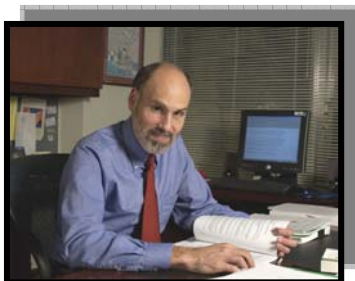
GENOME'S FRANCIS COLLINS TO STEP DOWN; GUTTMACHER TO BE ACTING DIRECTOR

On May 28, Francis Collins, director of the National Human Genome Institute (NHGRI), announced his intention to step down as director of the Institute on August 1, 2008. Collins explained that his decision to step down "came only after much personal deliberation and was driven by a desire for an interval of time dedicated to writing, reflection and exploration of other professional opportunities in the public and private sectors."



Francis Collins

Collins, a physician-geneticist, has served as NHGRI's director since April 1993. He led the Human Genome Project to its successful conclusion in 2003, and subsequently initiated and managed a wide range of projects that built upon the foundation laid by the sequencing of the human genome. In addition to his scientific leadership, Collins is known for his close attention to the ethical, legal, and social implications of genome research. He has also been a strong advocate for protecting the privacy of genetic information. He is recognized for his leadership in making the case for the Genetic Information Nondiscrimination Act of 2008, which was signed by the President last week nearly 13 years after it was first introduced in Congress.



Alan Guttmacher

"Francis has provided 15 years of outstanding leadership to NHGRI and has been a trailblazer in the scientific community at large," National Institutes of Health Director Elias A. Zerhouni noted. "His contributions to the world of genomics and medicine have been enormous."

Recently, Collins has also become a best-selling author, with his book [The Language of God: A Scientist Presents Evidence for Belief](#), an exploration of the relationship between science and religion.

Zerhouni announced that Alan E. Guttmacher, the current deputy director of NHGRI, will be appointed the acting director of the Institute on August 1. He also stated that a formal search process for a permanent NHGRI director will get underway shortly.

SRS DIVISION OF NSF LOOKS CLOSER AT CONFIDENTIALITY AND PRIVACY

Lynda Carlson, director of the Science Resources Statistics division, provided the following to Update

In the fall 2006 NSF's Division of Science Resources Statistics (SRS) in the context of heightened concerns about confidentiality/privacy completed a detailed review of its existing rules and procedures for protection of the data collected under a pledge of confidentiality in all its surveys. As a result of that review, SRS implemented more stringent procedures to protect the confidentiality of data provided by respondents to the Survey of Earned Doctorates (SED). The revised procedures resulted in suppressing more data cells with very small counts in tables in the 2006 SED Summary Report as well as in ones which individuals could special order from the survey contractor. The cells primarily affected were certain categories for the variables of race/ethnicity, citizenship and gender.

The issues and constraints relative to publishing small cell counts are very different for the SED than for the National Center for Education's Integrated Postsecondary Education Data System (IPEDS) data collection. For IPEDS aggregate data are supplied by institutions of higher education and there is no pledge of confidentiality to the institutions. For the SED, individuals supply information about themselves when they respond to the survey so the SED involves individual-level data and it is collected under a pledge of confidentiality to the individual respondent. The issues of protecting personally identifiable data supplied by SED respondents are heightened because the SED is a census of all individuals receiving a research doctorate in a given year. If a person received a research doctorate in a given year, it is known with certainty that individual is in the SED.

NSF received many complaints from the user community about the availability of less information from the SED than before, particularly for underrepresented minorities. A great deal of the concern related to the fact that SRS had implemented the changes without prior input from the user community. Users strongly suggested that SRS solicit user input as to how best to design the tables to meet a broad spectrum of user needs. NSF has listened to this concern. The following statement was released by NSF in early May.

SRS will be releasing the race/ethnicity, citizenship and gender data collected for the 2006 Survey of Earned Doctorates (SED) as in previous years. There are privacy and confidentiality issues that must be addressed, particularly in the context of small data sets. The question of how to aggregate the data in future years will be addressed with the data user community over the next few months and new tables will be developed to release data from the 2007 SED.

Tables containing 2006 SED data with the same level of detail as in previous years for race/ethnicity, citizenship and gender are available at the SRS website at http://www.nsf.gov/statistics/showsrvy.cfm?srvy_CatID=2&srvy_Seri=1.

The same web page has a comment box requesting suggestions for ways to redesign the tables presenting the SED data so as to address issues of both privacy/confidentiality and the needs of data users. SRS is also asking interested parties to take part in a small web survey on the same topic that will be conducted in the near future. COSSA members are encouraged to take advantage of both these opportunities to provide input to SRS' efforts.

In addition, SRS is engaging in a major outreach activity with users about the presentation of SED data and held their first meeting in early May. SRS would welcome input from COSSA members as it engages in this redesign activity. Is there an alternate venue we might use to meet with members, or do you have a special committee we might be able to communicate with? You may contact Lynda Carlson, the SRS Division Director, at (lcarlson@nsf.gov) or Jaqui Falkenheim, the SED Project Manager, at (jfalkenh@nsf.gov) to provide input or to set up a meeting.

The redesign of the tables for the 2007 SED Summary Report is likely to result in a delay of the 2007 report of at least several months until spring 2009. However, aggregate, national level 2007 SED data will be released as in the past in late fall in time for the annual Council of Graduate Schools (CGS) meeting, which has been a tradition. The exact nature of the late fall release is still under consideration but may involve a short report and a few high-level tables normally contained in the Summary Report.

2nd ANNUAL CONFERENCE ON INTERVENTIONS THAT ENCOURAGE MINORITIES TO PURSUE RESEARCH CAREERS

On May 2-4, the 2nd Annual Conference on Interventions that Encourage Minorities to Pursue Research Careers was held in Atlanta. Coming a year after the 2007 National Institutes of Health-(NIH) funded workshop on *Understanding Interventions* organized by the National Academy of Sciences in Washington, DC, the agenda of 2nd Annual Conference was intended to inform policy and practice, while fostering a multidisciplinary community of scholars dedicated to hypothesis-based investigations of what succeeds in recruiting and sustaining underrepresented students in the science, technology, engineering, and mathematics (STEM) pathway into the workforce (see Update, [May 28, 2007](#)). It also followed the February 28th retreat on Enhancing Diversity in Science (see Update, [March 24](#) and [April 7, 2008](#))

The meeting was organized by the Minorities Affairs Committee of the American Society for Cell Biology (ASCB) and a Planning Committee comprising members of the broader research and education communities, including COSSA's Deputy Director for Health Policy Angela Sharpe. More than 200 participants, including researchers, sponsors, program designers, evaluators, and policy analysts attended the meeting which featured a mix of plenary panels, concurrent mini-symposia, and posters detailing the knowledge base of investigative studies on approaches, mentoring, and publishing. The emphasis on "how to intervene" drew heavily on the literature from the social, behavioral, and economic sciences highlighting methodologies and outcomes in STEM.

The conference was funded by a grant from the National Institute of General Medical Sciences' (NIGMS) Minority Access to Research Careers program to ASCB. Welcoming participants to the meeting, co-chair of the organizing committee Anthony DePass of ASCB (Daryl Chubin of AAAS was the other co-chair) emphasized that there is "very valuable scholarship that relates to broadening participation" and that a goal of the meeting was to foster this community of scholars by bringing them together with the training community, to spread the results of the research.

The morning plenary, whose participants were sociologist Willie Pearson Jr. of the Georgia Institute of Technology, economist Samuel L. Myers, University of Minnesota, and psychologist Martin M. Chemers, UC-Santa Cruz, led off the meeting with a discussion of disciplinary and other perspectives on scholarship and its utilization in program design and outcomes.

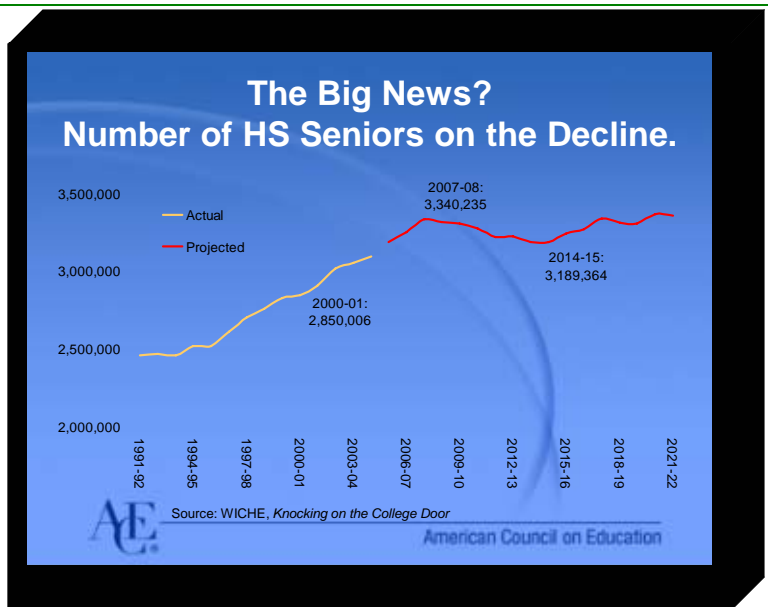
Pearson explained that in terms of the research, since the 1950s sociologists have produced work on various groups within the scientific community. It is only recently, he added, that systematic study has been done to focus on underrepresented minorities. He also related that not much has happened since his work in the late 1970s of the impact of race in the science and technical careers. There have been efforts to increase the numbers but that is not sufficient, Pearson insisted. He pointed out that we are limited by the data; a consistent refrain heard when discussions around broadening participation are held. Pearson also emphasized that there is more to learn about what has happened and what has impacted participation in these fields.

'Bottlenecks and Bulges: the Minority Academic Pipeline' and 'Obstacles to Achieving Faculty Diversity'

The meeting luncheon speakers were Brian Bridges, American Council on Education (ACE) Center for Racial and Ethnic Equity and economists William A. Darity, Jr.(Duke University), and Rhonda Vonshay Sharpe, (University of Vermont, Burlington).

Bridges discussed *Bottlenecks and Bulges: the Minority Academic Pipeline* ACE's Status Report on Minorities in Higher Education "considered to be the national source of information on current trends related to minorities in higher education." The Report is designed to focus national attention on critical higher education issues and promotes discussion about the implications of these issues for racially- and culturally-underserved communities, and for the nation as a whole, according to Bridges. The 22nd Status Report (2006) showed that minority enrollment at the nation's colleges and universities increased by 51 percent between 1993 and 2003, equivalent to approximately 1.6 million students. He informed the group that "minority growth in bachelor degree attainment for most disciplines - including computer sciences, business, and the social sciences - significantly outpaced that of majority students between 1993 and 2003."

According to Bridges, the data indicate that African Americans and Hispanics continue to lag behind their white counterparts in the rate of college-age, high school graduates enrolled in college and who complete degrees and the percentage of full- and part-time faculty. As of 2005, 69 percent of bachelor degree recipients and 81 percent of all full-time faculty were White. He explained that these numbers illustrate that while “bulges” of minority students exist at various places in the higher education pipeline (undergraduate enrollment, select masters degree programs), several “bottlenecks” (select masters degree programs, doctoral enrollment, faculty participation) continue to prevent the maximum participation of minorities at all levels of the academy.



The big news, Bridges informed the group is that the “number of high school seniors is on the decline.”

Using data from the Western Interstate Commission for Higher Education, Bridges noted estimates that between 2004/2005 and 2014/2015 the nation’s public high schools will produce: almost 207,000 (54 percent) more Hispanic graduates, nearly 46,000 (32 percent) more Asian/Pacific Islander graduates, about 12,000 (3 percent) more Black non-Hispanic graduates, approximately 2,000 (7 percent) more American Indian/Alaska Native graduates, and nearly 197,000 (11 percent) fewer White non-Hispanic graduates. Nevertheless, white students continue to make up the majority of enrolled college students. White males account for 4.5 million, white women 5.9 million, minority men 1.8 million and minority women 2.8 million of college students.

Darrity and Sharpe discussed their project looking at the “Obstacles to Achieving Faculty Diversity: Implications for Affirmative Action” funded by the Ford Foundation. The primary objective of the project is to gather information on the professional experience of Black/African-American, Hispanic, Native Americans and female doctorates in the social sciences and humanities who are citizens or permanent residents with a focus on the path of tenure track faculty and the factors causing and the magnitude of attrition at each stage of professional advancement. They are also interested in whether underrepresentation is exclusively a question of a conventionally construed pipeline problem or whether it is a question of outright exclusion on a discipline-by-discipline basis. The findings from this project have implications for more effective implementation for affirmative action with respect to the faculty pipeline.

Funding Interventions Research

Shiva Singh, Program Director in the Division of Minority Opportunities in Research (MORE) at the NIGMS, provided participants with a brief historical overview, the current status, and future outlook of the institute’s support of interventions research. According to Singh, for the past 35 years the NIH has supported a variety of programs to address the issue of underrepresented minorities in the sciences. Given that, Singh asked, what do we know about the various interventions? Are the assumptions on which they are built valid? There is a lack of empirical evidence, he informed participants, noting that “very little research” has been done to test the underlying assumptions of the interventions directed at this population. The Institute is seeking a research based understanding of interventions. In 2003 its advisory council approved the concept to address this issue. The funding opportunity announcement (FOA) has been through several revisions. Since the program’s inception, 11 research projects have been funded. These projects cover a variety of subjects. NIGMS plans to revise and release the FOA again in the summer of 2008. Shiva also announced the about-to-be-released FOA on “Research on Causal Factors and Interventions that Promote and Support the Careers of Women in Biomedical and Behavioral Research” (see Update, [May 19, 2008](#)).

Marc A. Nivet, Josiah Macy Jr. Foundation, shared his Foundation’s efforts in this area. The Foundation has focused heavily on collaboration, interdisciplinary research, and diversifying the health professions. It has also moved into the area of faculty development. “If we don’t begin to change the leadership, we will not be able to affect the change down the pipeline,” Nivet emphasized. He noted that the Foundation pulls together consortia to pool ideas. Unlike NIH, the grant guidelines for the Macy Foundation “are not as prescriptive to what you should be writing,” he explained. The Foundation sees itself as an innovator and venture capitalist. He invited participants to write to them directly and indicated that the Foundation will provide feedback on two-to-three page proposals. The funding cycles are two-three years and \$100,000-300,000 per year. He also highlighted the Foundation’s “staff grant” mechanism which allows for exploratory research. The Macy Foundation is interested in diversity and looking at the interface practice of the sciences, Nivet concluded.

Publishing Interventions Research

This meeting also addressed the issue of where to publish and access research on intervention. Michael Stevenson (Dean of the College of Social and Behavioral Sciences, Northern Arizona University), editor, of the newly created *Journal of Diversity in Higher Education (JDHE)*, informed participants that the journal is intended for a very large audience and is not just trying to reach people like them. Accordingly, the journal wants to publish a wide range of research. It is also trying to reach others who may be able to glean information from their work. And while the American Psychological Association is the publisher, Stevenson explained that the Journal is looking to hear from more than psychologists. He observed that there is more than one aspect of diversity, adding that at the same time the most interesting work is at the intersection of the issues. The Journal is also aimed at those who are interested in evidence-based practice. Stevenson underscored, indicating that his interest in promoting conversations across sectors within higher education. He related that there is exciting diversity-related work being done in small institutions. The scalability of the work, however, is a factor. He concluded his remarks by stressing that the goal of *JDHE* is to become the outlet of choice for people whose research is appropriate. He further indicated that he would “love to hear from people interested in participating in the review process.”

Rick Hoyle (Professor of Psychology and Neuroscience, Duke University) editor, of *Journal of Social Issues*, the flagship journal of the Society for Psychological Study of Social Issues (SPSSI), emphasized that the journal publishes research that offers a specific solution to a social problem. This includes basic to applied research. Hoyle emphasized that the mission of the *Journal of Social Issues* is to bring behavioral and social science theory, empirical evidence, and practice into focus on important human problems. The organization seeks ways to get that information into the hands of decision-makers, he added. He explained that every issue is thematic. There are 10 -13 articles on the same topic that is generated at the grass roots level. The editors of *JSI* look for issues that are broad ranging. With regards to the papers, every assertion is empirically based; every paper is examined for relevance and outcome of work, and culminates in various recommendations. He specifically highlighted the recent issue which focuses on “Unexpected Educational Pathways,” Volume 64, Number 1, 2008, as an example.

Additional information on the 2nd Annual Conference is posted at www.understandinginterventions.org. The website will be updated periodically as a portal to and discussion center about interventions targeted to STEM students, educators, and sponsors. Updates regarding the 3rd Annual Conference will be posted on the site beginning this summer.

NAS: THE NATIONAL CHILDREN’S STUDY RESEARCH PLAN OFFERS EXCELLENT OPPORTUNITY; ROOM FOR IMPROVEMENT

The National Children’s Study (NCS) “offers an excellent opportunity to examine the effects of environmental influences on child health and development, as well as to explore the complex interactions between genes and environments,” concluded a National Research Council of the National Academies Panel upon the release of its May 22, 2008, report. The review of the research plan to assess the scientific rigor of the study and the extent to which it is being carried out with methods, measures, and collection of data and specimens, to maximize the scientific yield of the study was requested by the *Eunice Kennedy Shriver* National Institute of Child and Human Development (see Update, [January 28, 2008](#)). “It is clear from our review that the National Children’s Study offers not only enormous potential, but also a large number of conceptual, methodological, and administrative challenges,” the Panel concluded.

The NCS is the largest long-term study of environmental and genetic effects on children’s health ever conducted in the United States. The study will explore a broad range of environmental factors that could influence the health and development of children. Environment is broadly defined by the Study to include biological, chemical, physical, social and behavioral influences on children. The broad range of outcomes includes obesity, diabetes and physical development; injuries; asthma; pregnancy-related outcomes; and mental health issues. Details regarding the design and methods for the NCS are available in the study’s Research Plan on the study’s website at www.nationalchildrensstudy.gov.

The review was conducted by the National Academies’ Committee on National Statistics, in collaboration with the Board on Children, Youth, and Families of the NRC and the Institute of Medicine (IOM) and the IOM Board on Population Health and Public Health Practice. Samuel H. Preston, University of Pennsylvania, served as chair of the Panel to Review the National Children’s Study Research Plan. Topics addressed included proposed outcomes and hypotheses; proposed measures of environmental exposure; genetic makeup, family and community environment, and personal characteristics; proposed data collection and analysis methods; and other aspects of the research plan.

Study's Strengths

The review Panel concluded that the stated goals for the NCS, and the design of the NCS for achieving those goals, broadly reflect the stipulations of the Children's Health Act, which authorizes the study. A longitudinal study designed to follow the births of 100,000 children until the age of 22 "would provide enough statistical power to examine many hypothesized relations that cannot be investigated with smaller samples." The Panel notes that "a data set that contains data gathered prospectively over the entire course of pregnancy, childhood, adolescence, and early adulthood will enable many new life-cycle relations between exposures and outcomes to be investigated." It is also highlighted that a "particularly attractive feature of the study is the effort to recruit births before conception and during very early periods of gestation, when certain environmental exposures may prove to be critically important."

An additional strength of the study highlighted by the Panel is the "enormous array of social, psychological, biological, chemical, and physical measures that will be generated under present plans will permit investigation of relationships that have not previously been studied." Noting that the NCS is a "well-designed national probability sample," the Panel emphasizes that the use of established random selection methods at each sampling stage will ensure that the NCS samples of households, eligible women of childbearing age, and births are national probability samples. The Study's use of "probability sampling without oversampling any group is endorsed." The review Panel stressed, however, that it is "important to note that the sample size and sampling scheme of the study represent a compromise and are not designed to address any single hypothesis."

'Weaknesses and Shortcomings'

The review Panel cited nine "weaknesses and shortcomings" associated with the study:

1. **The absence of an adequate pilot phase.** The study design is extremely complex in terms of identifying subjects, enlisting their enrollment and continued participation, administering the very large number of survey and clinical instruments, and managing huge databases generated by disparate organizations. Many questions are raised about the instruments that have been chosen and the timing of their application. The Panel thinks that if the study is to achieve its promise, experimentation is needed with respect to methods to increase response rates and data instruments. Many of these concerns could be addressed in a pilot phase, it is noted.
2. **Decentralization of data collection.** This unusually decentralized data collection strategy reduces the chances that data will be of uniformly high quality over the life of the study and sharply increases the burden of supervision. The centralized and conventional model employed by the National Longitudinal Study of Adolescent Health is cited as one that "appears more likely to produce high-quality data." But given that contracts have already been signed, "it will be incumbent upon the government to ensure that staff and other resources are sufficient to closely monitor data collection activities and take prompt remedial steps as necessary."
3. **Inadequacy of plans to maximize response rates and retention rates.** The NCS research plan does not explicitly address the best methods and procedures for achieving the ambitious baseline response rates that are targeted. Maintaining the representativeness of the sample over time is key to the quality of the results. Little is said in the research plan about how the study expects to maximize retention of sample cases.
4. **Weakness of conceptual model.** The research plan does not define the basic concepts of health and development. The plan frequently defaults to a deficit model that focuses on disease and impairment and the risk factors that contribute to them, rather than on the factors that encourage healthy development. There is an imbalance of hypotheses with specific hypotheses about disease conditions and vague hypotheses about social environments and children's intellectual and social development. There is a similar imbalance with the measures selected. Little attention is given to outcomes in later childhood and adolescence that might have encouraged attention to additional or alternative exposures.
5. **Weakness of certain data instruments.** The review revealed gaps, uncertainties, and insufficient rationales for a substantial number of instruments. Even when suitable measures have been selected, the timing of their deployment, as proposed in the research plan, will leave large gaps in the measured trajectories of child health and development.
6. **Insufficient attention to racial, ethnic, and other disparities.** "The Children's Health Act asks the study to 'consider health disparities among children,' a phrase that typically directs attention to racial and ethnic disparities and can also include language, socioeconomic, and geographic area disparities." The panel noted that the research design was not informed by a concern with understanding this factor. In particular, there is no attention to generating data on how individuals from different groups may interact with health systems, a factor

whose importance has been suggested in many previous studies. There is also no attention to psychosocial experiences that differentiate among population groups.

7. **Failure to adequately integrate data from medical records.** High-quality information about the use of medical services would help to address major questions in health policy. Records from physicians and hospitals, while expensive to collect and mobilize and, which are imperfect, would provide an extremely valuable and sometimes indispensable supplement to the retrospective reports of parents. It is urged that greater attention be paid to incorporating such data.
8. **Failure to plan adequately for disclosure of risk to participants.** Clearer plans must be developed regarding what parents and children need to be told about emerging *research* findings.
9. **Failure to plan for rapid dissemination of data.** The Panel thinks that the present plan is unwise in reserving a period of time associated with the data collection phase of the study to have exclusive access to its data for analytic purposes. "Such a practice slows the advance of science and violates increasingly widespread norms, including those prominent within the National Institutes of Health itself." The review plan "urges wide and rapid dissemination of the data produced by the study."

Recommendations

The Panel strongly urge[d] the NCS to delay enrollment at new sites to make effective use of initial findings from participant enrollment and data collection in the Vanguard Center sites to improve study procedures, as appropriate, and to refine key concepts, hypotheses, and measures of outcomes and exposures. Throughout the life of the study, the NCS should use the Vanguard Centers to pilot test and experiment with the data collection methods and instrumentations (Rec. 2-4).

The Panel also recommended (Rec. 4-1) that the "NCS should consider modifying the sampling design to allow for flexibility increasing the number of study participants in the event that the estimated number of screened households needed to reach 1,000 births per primary sampling unit is incorrect."

In total, the Panel made 24 recommendations around the goals of the study; conceptual framework; the Vanguard Centers; pregnancy outcomes; neurodevelopment and behavior and child health and development; asthma; obesity and growth; injury; hormonally active agents and reproductive development; demographic and socioeconomic, chemical exposure, physical exposure, psychosocial exposure, biological exposures, genetic, and missing exposure measures; data linkages; sampling design; data collection; data analysis and dissemination; criteria for giving information to participants; protection and release of information; and informed consent.

NCS Study Director Peter Scheidt responded that the "National Children's Study is very pleased with the NAS review and feels that it clearly met the objectives for performing it." Scheidt was especially pleased with affirmation that the Study should be carried out and that the general approaches were found to be appropriate (size, representative sample, and priority exposures and outcomes included). Though some of the noted weaknesses and recommendations are either already being addressed or would require substantial additional resources to implement, a number of the recommendations point to ways that the Study can be improved and the Study more optimized, he stated. Scheidt concluded that: "We welcome these recommendations and where possible will be incorporating them into the Study accordingly."

A free copy (PDF) of the NAS report can be downloaded from <http://www.nap.edu/catalog/122.html>.

THE CONDITION OF EDUCATION 2008 REPORT RELEASED

The Condition of Education 2008: Enrollment, Student Diversity on the Rise was released by The National Center for Education Statistics on May 29. The Condition of Education is a congressionally mandated report that provides an annual portrait of the state of education in America. The full report is available at <http://nces.ed.gov/programs/coe> or by calling 877-4-EDPUBS for a free printed copy.

NATIONAL ADVISORY PANEL REPORT CALLS FOR MORE RESEARCH ON MATH TEACHING AND LEARNING

On May 13, the National Mathematics Advisory Panel released its final report. The panel established by President Bush in April of 2006, was charged with providing recommendations on the best use of scientifically based research to advance the teaching and learning of mathematics. On May 21, the House Education and Labor Committee held a hearing on the Panel's report.

Chairman Rep. George Miller (D-CA) stressed the need to raise not only our math education standards, but also expectations for math education. He called for reforming the current math curriculum structure to make it more conducive to helping students build their math skills over time. "I hope that the National Math Panel's report serves not just as a wake-up call, but as a catalyst for the significant changes needed to help reach that goal," said Chairman Miller.

As part of the effort to improve math education in the U.S., the America COMPETES legislation calls for funding the Math Now Initiative at \$95 million. The Math Now Initiative seeks to improve math education at the elementary and middle levels to help ensure all students become proficient in math. The initiative would also provide teachers with research-based tools and professional development.

According to the report, more curricular focus and coherence is needed in math education. Currently, teachers are guided by state curriculum standards that require more than 100 learning expectations per grade level. This chaotic approach results in limited time given to each topic area, and a lack of depth in exploring these areas. The Math Panel's report calls for a more focused, coherent curriculum in grades pre-K-8, and a streamlined well-defined set of topics that should be emphasized in the early grades. The early years of a student's math education is the foundation to later success in algebra and other STEM subjects. Early childhood educators should actively introduce mathematical concepts, methods, and language to students. This would help students prepare better for Algebra by the 8th grade, a goal the Advisory Panel seeks. Algebra is the gateway to higher level mathematics, and research shows that the completion of Algebra II correlates significantly with later success in college and future employment earnings. According to Francis Fennell of McDaniel College, "students who complete Algebra II are more than twice as likely to graduate from college compared to students with less mathematical preparation."

The Advisory Panel recommends that teachers be given opportunities to learn math for teaching. Teachers are the most important factor in student learning, yet they do not receive the training and support they need to provide effective math instruction. Many math teachers are not knowledgeable beyond the basics. More needs to be done to provide teachers with opportunities to learn higher level math and to participate in professional development programs. Research has indicated that the single most important factor in mathematics learning is teacher quality. However, the studies have not shown us what makes an effective math teacher or even how they generate student achievement. The panel argued that more research is necessary and support should be provided to encourage schools to participate in educational research. We must continue to build the capacity for more rigorous research in mathematics education to more effectively inform both policy and practice.

Rep. Rush Holt (D-NJ) said that: "We have to spend some billions of dollars in education research. We needed to make a major commitment to research. This culture needs to be more firmly grounded in research, especially as technology improves."

Mary Ann Wolf, of the State Educational Technology Directors Association (SETDA), testified that the education community needs to invest in technology and embrace its uses. A Department of Commerce study showed that education was actually 55 out of 55 industries studied in use of technology. Utilizing technology does not mean just putting computers in the classroom, it involves changing the way teachers teach and students learn. According to Wolf "understanding is increased when students and teachers use and apply technology to investigate mathematical concepts". Unfortunately many school districts can't offer technology programs due to the high cost of equipment, and the inequities in school funding, inequities that exist across the nation, within states, and even within the same city.

The Bureau of Labor Statistics projects that science and engineering employment in the United States will increase 70 percent faster than the rate for all other occupations in the next decade. The Business Roundtable's program Tapping America's Potential goal is increasing the number of Americans graduating with an undergraduate degree in the STEM fields from the current level of 225,000 a year to 400,000 a year by 2015. John Castellani of the Business Roundtable testified that currently only seven percent of U.S. college students major in math or science fields, and that this number decreases to three percent by the end of their first year of college. Castellani informed the committee that more than 57 percent of post-doctoral engineering students are from outside of the U.S., and while U.S. Patent applications from

Asian countries have grown by 759 percent from 1989 to 2001, the patent applications from inside the U.S. during the same period grew at only 116 percent.

One of the most important findings in the Advisory Panel's report is that student effort matters. The report states that "mathematics education is based on the erroneous idea that success comes from inherent talent or ability in mathematics, not effort. A focus on the importance of effort in mathematics learning will improve outcomes." Math is a critical gateway not only to the learning and educational success in every STEM field, but also according to Fennell, "for a better, stronger workforce, and a stable, well-informed citizenry."

For the National Mathematics Advisory Panel's executive summary and full report go to www.ed.gov/MathPanel.

CONGRESSIONAL BRIEFING EXAMINES LACK OF GERIATRIC CARE FOR AN INCREASING ELDERLY POPULATION

Last year the Institute of Medicine (IOM) embarked on a project to examine the optimal health care workforce for older Americans in an aging society. Under the leadership of committee chair Jack W. Rowe of the Committee on the Future, 15 experts met to address those needs through a thorough analysis of the forces that shape the health care workforce, including education, training modes of practice, and financing of public and private programs.

The results were included in a report titled *Retooling for an Aging America: Building the Health Care Workforce*. The report alludes to a healthcare crisis that will impact older adults and their families nationwide. This is the shortage in physicians with a specialty in geriatrics for a growing elderly population. The crisis is even more acute for geriatric psychiatrists to deal with the difficult mental health questions affecting older Americans. The report also examined the need to improve public programs to encourage more training of geriatricians, the committee also took a closer look at Medicare and Medicaid and the costs associated with extra years of geriatric training.

Bruce Pollock, President of the Association of Directors of Geriatric Academic Programs (ADGAP), explained that while the demand for specialized mental health care is sufficient, physicians face financial disincentives to entering the field of geriatric psychiatry such as annual scheduled cuts to Medicare physician payments and discriminatory coverage of mental health benefits under Medicare, affecting providers as well as patients. "While the demand for specialized mental health care is great, physicians face several financial disincentives to entering the field of geriatric psychiatry such as annual scheduled cuts to Medicare physician payments and discriminatory coverage of mental health benefits under Medicare."

In a May 15th Congressional briefing entitled "Meeting the Health Needs of an Aging America: Opportunities and Challenges for Federal Policy," ADGAP President-Elect and professor of psychiatry, neurology and neuroscience at the University of Pittsburgh School of Medicine Charles Reynolds spoke further on the geriatric mental health workforce crisis urging Congress, regulatory agencies and health care leaders to act upon the IOM's report and make the necessary changes to recruit and retain a skilled workforce in geriatrics and geriatric mental health care, and to adopt an efficient and effective organization for geriatric medical and mental health care services. "Unless changes are made now, older Americans will face long waits, decreased choice and suboptimal care," Reynolds argued.

Co-sponsored by the ADAGP, the American Psychological Association (APA), the National Association of Social Workers (NASW), and the Older Women's League (OWL), the briefing aimed to educate Congress on federal policies that can both prevent and support the needs of the aging population from being addressed.

Toni Antonucci of APA and the University of Michigan discussed the Integrated Health Care model as key to achieving optimal care for the aging population. This model emphasizes a high degree of collaboration in assessment, treatment planning, implementation, and outcome evaluation across health professionals. It encourages the delivery of care in a person-centered, culturally-competent manner that encompasses older adult preferences and values. More specifically, it includes a diverse group of team members such as physicians, psychologists, social workers, occupational therapists and physical therapists depending on the needs of the individual. "Integrated health care works," said Antonucci, "but more research is needed."

The integrated model is the result of the APA Integrated Health Care for an Aging Population (IHAP) Initiative. Established as one of the 2007 APA Presidential Initiatives, the task force examined and developed recommendations for how psychologists can work with other health care professionals, individuals and families to ensure appropriate, effective, and integrated healthcare for the increasing number of older adults. Out of the IHAP initiative came the report, *Blueprint for Change: Achieving Integrative Health Care for an Aging Population* which can be found on APA's website at www.apa.gov.

NIH EXPANDS CTSA CONSORTIUM

On May 29, the National Institutes of Health (NIH) announced that 14 academic health centers in 11 states have been awarded the NIH's Clinical and Translational Science Award (CTSA). Led by the NIH's National Center for Research Resources (NCRR), the CTSA's are designed to reduce the time it takes for laboratory discoveries to become treatments for patients and to engage communities in clinical research efforts. "The consortium serves as the bridge in this process that allows researchers to perfect and refine existing treatments through interdisciplinary teams that extend to the clinic and the community," according to the NIH Director Elias Zerhouni. The 14 institutions receiving the new CTSA funding include:

Albert Einstein College of Medicine of Yeshiva University
Boston University
Harvard University
Indiana University School of Medicine
Northwestern University
The Ohio State University
The Scripps Research Institute
Stanford University
Tufts University
The University of Alabama at Birmingham
University of Colorado Denver
The University of North Carolina at Chapel Hill
The University of Texas Health Science Center at San Antonio
The University of Utah

The 14 centers join the 24 others announced in 2006 and 2007 (see Update, [September 24, 2007](#)). In addition to expanding the state representation, the 2008 CTSA grants also support pediatric research at 13 dedicated children's hospitals; expand research in genetics and genomics; enhance research in behavioral immunology and infection risk; and increase outreach into local communities.

A fourth funding opportunity announcement for CTSA's is available, calling for the next round of applications to be submitted by June 17, 2008, with the awards expected in March 2009. For more information about the announcement see www.ncrr.nih.gov/crfunding. For more information on the CTSA's visit www.ncrr.nih.gov/crctsa.

NIH, AHRQ TO HOLD 2008 DIABETES AND OBESITY DISPARITIES IN HEALTHCARE SYSTEMS CONFERENCE

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Center on Minority Health and Health Disparities (NCMHD), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ) are sponsoring a day and a half conference, June 30-July 1, 2008, designed to promote healthcare-based research aimed at reducing or eliminating disparities in diabetes and obesity-related outcomes. The conference will feature presentations about important factors in healthcare-based disparities research. In addition, there will also be a discussion of unique design, measurement, and methodology issues.

Concurrent with the conference, NIDDK has issued a Program Announcement (PA) (<http://grants.nih.gov/grants/guide/pa-files/PA-07-388.html>) for investigator-initiated research on identifying and reducing diabetes and obesity-related health disparities within healthcare systems. Topics of interest include:

- The Importance Of A Healthcare Systems Approach - epidemiology, adults, children, and adolescents
- Research Framework - conference model
- Healthcare System Factors/Health Services Research
- Healthcare Team Factors
- Patient-Level Factors - children and adults
- Community-Level Factors
- Community-Based Participatory Research
- Multifactorial Research

- Research Design and Measurement Issues
- Special Issues Across the Lifespan
- Interventions in Adults and Pediatrics
- Cultural Tailoring and Audience Segmentation
- Linking to the Community
- Data Linking and Analysis with Multiple Levels of Data

For more information and/or to register for the conference see:
<http://www3.niddk.nih.gov/fund/other/healthcaredisparities2008/>

The John M. Eisenberg Center for Clinical Decisions and Communications Sciences

AHRQ is also soliciting proposals to establish a research and translation decision science and communication center that will facilitate access to evidence-based clinical and health care delivery information, and foster informed health care decisions by patients, providers, and policy makers. The Center will work with AHRQ and its contractors to implement Section 1013 of the Medicare Modernization Act of 2003.

It is anticipated that a solo contract will be awarded for a period of 2 years with 3-one year option periods. The Award is expected no later than August 15, 2008. In addition to the solicitation's availability on AHRQ's website (www.ahrq.gov), it will also be available for downloading from the internet on the FedBizOps website at www.fbo.gov. It is the offerors' responsibility to monitor this site for release of the solicitation, download their own copy of the solicitation, and monitor the site for any subsequent amendments. Since it is not known who is downloading the solicitation, a bidders list will not be available. All responsible businesses may submit a proposal which will be evaluated by AHRQ.

WEB DISCUSSION OF NIH RESEARCH, CONDITION, AND DISEASE CATEGORIZATION PLANNED JUNE 11

On June 11, 2008, 2:00 - 3:00 pm (EDT), the National Institutes of Health (NIH) is planning to hold a webinar (web-based videocast) to introduce the agency's new Research, Condition, and Disease Categorization (RCDC) system. A computer-based tool, the system is designed to allow users to see how the NIH categorizes its research in nearly 360 categories representing research areas, diseases, and conditions.

Alan Krensky, Director of the NIH Office of Portfolio Analysis and Strategic Initiatives (OPASI), and Tim Hays, Project Director for RCDC, OPASI, will explain the RCDC system and then lead an open discussion. Time will be allocated for questions and answers. To participate in the webinar, RSVPs are required by Friday, June 6, 2008 to rcdcpublicinfo@mail.nih.gov. Please note that agency's capacity is limited by its web servers, so you are encouraged to respond early. Questions may be submitted in advance to rcdcpublicinfo@mail.nih.gov.

In addition, included in the announcement regarding the webinar, the agency notes that some of the research funding that the RCDC system will report may differ from NIH reports issued in the past. That is because RCDC will sort funded research using a new method. The way NIH budgets and spends tax dollars, however, will not change.

In spring 2009, the agency plans to post the first RCDC reports from FY 2008- funded research on a public website. Users will be able to view, print, and download these detailed reports. Information and updates will be posted at rcdc.nih.gov.

EDITORS NOTE: CORRECTION

In the Volume 27, Issue 9 Edition of COSSA Washington Update, it was reported the article entitled *Marburger Reflects on Science Policy at AAAS Forum*, that Marburger referenced an article by biologist Blaine Harden in SCIENCE magazine from 1968 called "The Tragedy of the Commons." Correction: Garrett Harden is the author of *The Tragedy of the Commons*.

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