

# Report of the NINDS Advisory Panel on Health Disparities Research

## **NINDS Advisory Panel on Health Disparities Research**

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## I. Introduction

In 2010 the NINDS Director convened an external panel to review and provide recommendations to NINDS with respect to the priority, administration and oversight of health disparities research conducted by NINDS. The panel met in person for a two-day meeting in May 2010, and had access to detailed records of NINDS efforts involving health disparities research in the past. The current panel's report was divided into six sections: vision, strategic plan and priorities; organizational structure, scope and collaboration; evaluation and accountability; training; recruitment, enrollment and retention into clinical trials; and community education. Two members of the panel were assigned to write drafts of each respective section. These section drafts were circulated for feedback to the entire panel and revised accordingly. The revised section drafts were organized into a complete draft report by the panel Chair and circulated to the entire panel. In October, the panel met by conference call to discuss each section. Based on the written and verbal comments from the panel, the Chair revised the report. The report will be presented to NINDS Council in February, 2011.

This report will first summarize the findings and provide the 20 major recommendations included in the six sections described above. Following this, a detailed review of health disparities research at NINDS and more detailed suggestions will be provided.

## II. Summary and Recommendations

### *a. Vision, strategic plan and priorities*

#### Summary

At the meeting in May, 2010 and after extensive review of the documents provided by NINDS there does not appear to be a clearly stated vision or strategic plan by which NINDS conducts health disparities research. It is obvious, however, that the Director feels that this is a high priority area from the fact that she has convened this panel and clearly speaks to the importance of this line of research going forward in the NINDS portfolio.

#### Recommendations

1. We propose the following vision statement for health disparities research at NINDS—*The National Institute of Neurological Disorders and Stroke is deeply committed to the elimination of health disparities through the funding of high level research from basic science through outcomes research aimed at identifying, monitoring and targeting biologic, environmental, social and healthcare system*

*factors that confer neurologic disease and its treatment disproportionately and adversely to underserved minority populations.*

2. A clear strategic plan should be enumerated to document the approach to a coordinated plan for research in health disparities. This should include all elements from basic science through health services research, and all types of awards from training through center grants.
3. A systematic priority-setting process for health disparities research should be established that is data-driven, standardized, transparent, and brings to the table a range of perspectives. The priority-setting process should identify for further consideration those conditions or groups of conditions with high overall burden of disease and for which there are potentially unique health disparities issues due to the nature of the neurologic condition (e.g., stigma associated with epilepsy). The process should involve stakeholders in formally ranking priority areas or conditions and be documented in writing. The priority-setting process should be updated internally annually and overall every 3 years. Involvement of outside experts to conduct systematic literature reviews and perform asset mapping to support the priority-setting process should be considered.
4. While the priority-setting process is underway, a review of new and ongoing disease-specific initiatives within NINDS for possible incorporation in health disparities research, for example, the Epilepsy Centers without Walls, should be performed.

#### *b. Organizational structure, scope and collaboration*

##### Summary

Based on information provided to the committee, it appears that health disparities research is sparse at NINDS, and what little there is spreads throughout NINDS across Offices and Clusters. The role that the Office of Minority Health and Research (OMHR) has played in designing initiatives and fostering programs in health disparities research has been relatively isolated from other parts of the institute.

##### Recommendations

5. Establish a new distinct office for health disparities research whose leader will report directly to the NINDS Director.

6. The scope of work should include all research that is designed to *directly* investigate health disparities. A detailed, collaborative, program officer support structure from the clusters is necessary for this new office to provide guidance for scientists contemplating grant submission in the broad spectrum of science that falls under the rubric of health disparities research.
7. Important direct NIH partnerships would be a) National Institute on Minority Health and Health Disparities (NIMHD), b) Other Institutes and Centers (ICs) (National Heart, Lung and Blood Institute (NHLBI), etc.). A main objective would be to make all NINDS personnel leading health disparities research aware of what is happening both at NIH and other places within the Department of Health and Human Services (DHHS) (e.g. the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Disease Control and Prevention (CDC)), as well as in non-governmental organizations (NGOs) that conduct or support health disparities research. A dedicated analyst to track these developments is needed, and should be the beginning of ongoing active collaborations between NINDS and the agencies mentioned above.

### *c. Evaluation and accountability*

#### Summary

A structured approach to track and evaluate the success of health disparities research initiatives is not apparent.

#### Recommendations

8. Clear metrics of success and impact (e.g., Requests for Applications (RFAs) launched, responses to RFAs, funded applications, papers produced from funded research, findings of relevance to policy-makers, clinicians and patients/patient advocates) should be defined, implemented and tracked.
9. To the degree that population-based surveillance data are available on the metrics of health disparities for neurologic conditions, monitor these data to determine if NINDS-targeted areas of disparities research show evidence of meeting the needs of the communities that are affected. Identify and support opportunities to collaborate with agencies such as the CDC to expand the ascertainment of selected surveillance data.

10. These metrics should be developed through a transparent process with both internal and external advice and with input and approval by Council. A full process of development should occur every three years with yearly updates.
11. The health disparities research office should be accountable to the NINDS Director with respect to progress on achieving the metrics and defined goals, and provide annual reports to Council for advisory feedback as well. Yearly adjustments should be made as needed to accomplish the set targets.

#### *d. Training*

##### Summary

While structures exist for workforce diversity, there are no specific mechanisms for training future health disparities researchers.

##### Recommendations

12. Training in health disparities research in the clinical and basic neuroscience should be a high priority at NINDS with specific RFAs and sponsored workshops in this area.
13. An NINDS staff member, in the new office for health disparities research, should be readily available to answer questions about training opportunities at the Institute specific to health disparities research. This person should work closely with and be embraced by the Office of Training and Career Development.
14. Utilize existing training mechanisms in basic, translational and clinical science – Pre-doctoral and Post-doctoral Fellowships (F31, F32), Mentored Career Development Awards (K01, K08, K23, K25, K99), Independent Scientist Awards (K02, K24, R15) and Institutional Training Programs (T32, K12, R25) – to train both early and mid-career investigators in health disparities research. To increase the number of successfully funded applications in health disparities research, we recommend that the NINDS issue an NIH Guide Notice on the NIH Parent Announcement(s) to announce that health disparities research is of particular interest to the Institute. Reviewers with scientific expertise in health disparities research should be included on relevant study sections.

*e. Recruitment, enrollment and retention in clinical trials*

Summary

There have been improvements in the enrollment of African Americans and women in NINDS funded clinical trials. There remains low enrollment of Hispanic Americans in these trials, and poor reporting of race/ethnic specific data in publications from these studies.

Recommendations

15. Provide a training module to researchers and their project management staff on effective strategies for recruitment of these populations.
16. Include the human subjects section, and specifically the section on efforts to recruit a diverse subject population, as part of the overall scoring of grant applications, if possible, recognizing this would likely be an NIH-wide policy change. Internally, strongly encourage program officers to hold applicants to NIH requirements for specifying methods of minority recruitment and for justifying any exclusions. Require progress and final reports to include a description of the success AND the failures in recruitment, and create a repository of these data accessible to researchers and potentially the public.
17. Funded investigators should be encouraged to publish race/ethnic specific data.

*f. Community education, and dissemination of health disparities research findings to healthcare professionals and to policy-makers*

Summary

Community education should be evidence-driven and provide community residents with education and motivation to seek improved neurologic health. There are key scientific behavior change principles that should drive community education. Findings from NINDS-funded studies should be the focus of the messages. The audience for these research findings should specifically include not only the public but also healthcare professionals and administrators, and policy-makers – that is, all stakeholders who can use NINDS-supported research findings to effect changes in behavior and in policy to effect reduction or elimination of disparities in the burden of neurologic disease in the population.

## Recommendations

18. Awareness of what has been learned over the years begins with a search of the scientific literature and examination of what other institutions and entities are doing with regard to community outreach for minority populations. For each of your audiences, it is important to know:
  - The channels of communication (e.g., mass media, Internet, print materials, person-to-person)
  - The various venues for communicating with target groups (e.g., home, workplace, clinics, schools, churches, businesses)
  - Preferred information communication means (e.g., television, radio, newspapers, Internet)
  - How individuals currently receive health information (e.g., media, physicians and staffs, Internet, family, friends)
19. Employ sound scientific principles. Every step and every aspect of community outreach should be driven by research.
20. Partnering with other institutes, other branches of DHHS (including CDC), and NGOs involved in providing health messages to minority populations and disseminating research findings on new knowledge about how to redress disparities in health for persons with neurological conditions is crucial. Adding NINDS messages to existing external efforts of partners may provide an efficient way to use resources to inform, educate and motivate the public, healthcare professionals and administrators, and policy-makers about NINDS research findings on health disparities.



### III. Detailed Discussion

#### *a. Background and context*

Our panel was charged with making specific and general, “practical and actionable,” recommendations on health disparities research that can guide NINDS in meeting its mission, “to reduce the burden of neurological disease through research.” NINDS developed a prior strategic plan on health disparities in 2001, which was expanded in 2003 and is analyzed in this report (National Institute of Neurological Disorders and Stroke, 2003).

The Advisory Panel as a whole received its charge from the Director, Dr. Landis, who asked us to be candid and to, “think as broadly as you can for the whole community,” with respect to recommendations regarding the unique role of NINDS in health disparities research. The panel was also asked to address strategies for broadly increasing minority recruitment into its clinical trials. The panel was asked to provide critical analysis of the extent of success of current programs and investments, and to make recommendations about how it, “can more effectively support its mission in relation to the reduction of health disparities,” specifically: (1) short-term and long-term priorities and strategies in research and training, including re-organization of current internal processes, if needed, and (2) ongoing evaluation.

Finally, the panel is mindful that all this is in the setting of a budget climate unlikely to see significant increases in the near future. The panel was advised that strategies that would leverage resources or infrastructure across institutes and agencies would be particularly welcomed.

#### *b. Definitions and conceptual model for health disparities and health disparities research*

##### Definitions

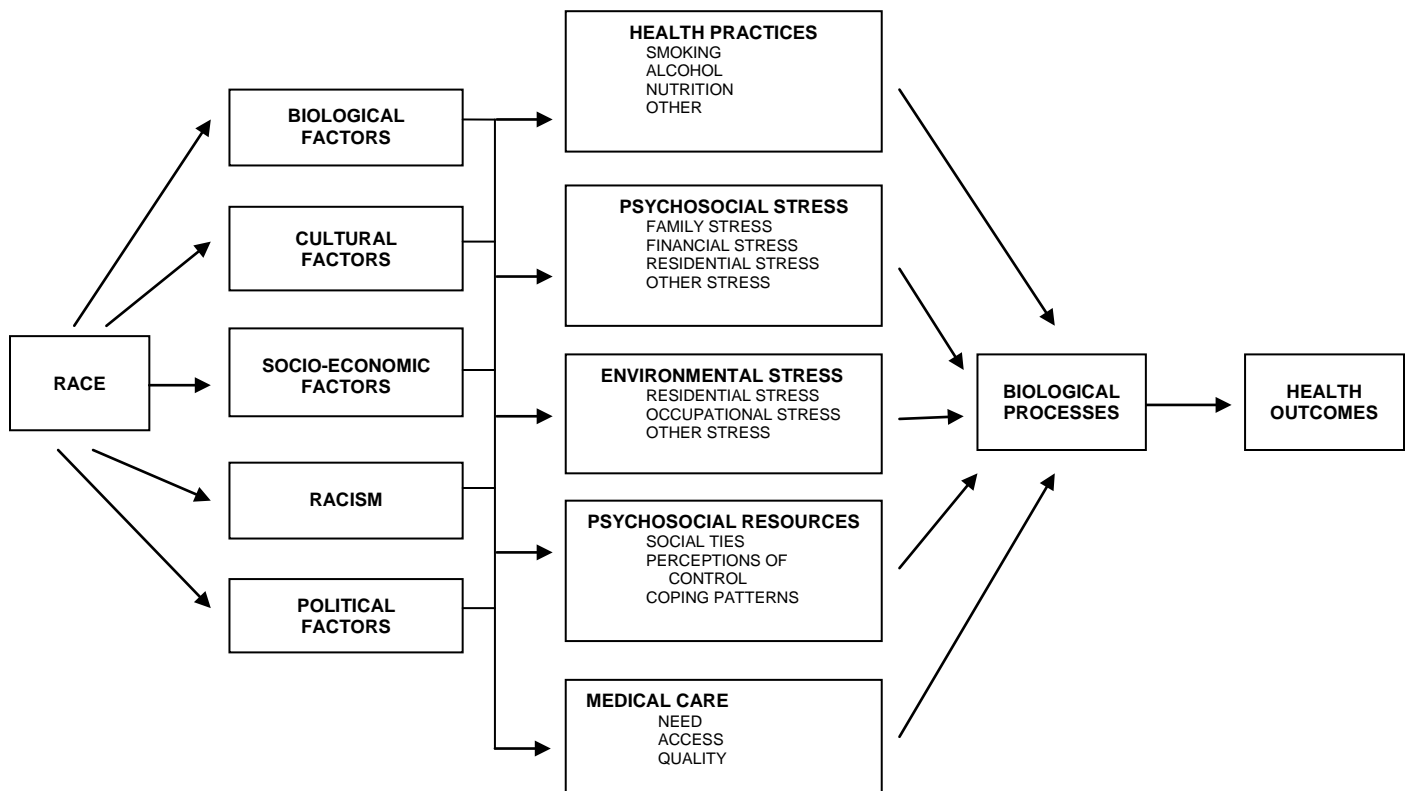
The panel judged that “health disparities” and “health disparities research” needed to be defined, and that how health disparities research relates to the NINDS mission needed to be made explicit. New knowledge on causes and effective interventions that reduce health disparities (“studies whose purpose is to address *a priori* research questions uniquely affecting ethnic minority and medically underserved groups”) was the Institute of Medicine’s recommended definition for what constitutes health disparities research (Institute of Medicine, 1999), according to the 2004 Final Report of the NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology. The framework described in the King’s Fund report from the UK (Benzeval et al., 1995)

posits four possible causal pathways for health disparities. Two of these – inadequacies in the physical environment (such as housing) and inequalities in social and economic factors (such as income) – are in general beyond the scope of health-related research to address. However, health disparities research that measures differences in health across disadvantaged populations and analyzes whether they are attributable to decreased access to needed health care services or due to higher occurrence of behavioral risk factors for disease are prime targets of health-related research (Institute of Medicine, 2003); designing, testing, and disseminating effective behavioral, healthcare delivery, or policy interventions to redress these disparities and improve health outcomes for neurologic conditions is thus clearly within the scope of NINDS’ mission (Cooper et al., 2002; Vickrey and Shapiro, 2009). Further, there are some clear biological underpinnings of different disease burden and presentation. For example, atherosclerosis appears to be deposited differentially in the intra-cranial and extra-cranial circulation among different race/ethnic groups. This argues for the need of basic science investigations in addition to epidemiologic and health services research approaches to health disparities.

Conceptual Model

One of several conceptual models for understanding disparities in health related to race/ethnicity is shown below (King and Williams, 1995):

**A Framework for Understanding the Relationship Between Race and Health**



It is clear from this model that there are many social, economic, and behavioral factors that drive associations of race and health; these associations are not solely biological. Given that, there needs to be research that involves social science and related disciplines, in order to redress health disparities. As the NIH Health Disparities Strategic Plan of 2004-2008 stated (National Institutes of Health, 2008; page 21), “ICs that are traditionally biological must develop an increased awareness of, and an integration with, the non-biological disease factors contributing to disease.”

### What is the Value of Research on Health Disparities?

Such research should be conducted in order to acquire new knowledge that will lead to elimination of racial/ethnic and other disparities in health outcomes for persons with neurologic disease. In 2004, Steven Woolf, David Satcher, and others published a brief that projected the number of lives saved in the US from 1991 to 2000 due to advances in medical drugs and devices, and compared this to the number of deaths attributable to higher mortality in African-Americans compared to whites over the same period: while an estimated 176,633 lives were saved by the new drugs and devices over this period, an estimated 886,202 deaths would have been averted had the disparities in health of African-Americans in this time period been eliminated (Woolf et al., 2004).

### Example of High-Impact Disparities Research Outside of Neurology

An example from research on racial/ethnic disparities in HIV care in the US that had a substantial impact on policy and healthcare was the HealthCare Services and Utilization Study (HCSUS). This observational cohort study identified a national probability sample of people in care for HIV in the US and followed them for two years. During the study period, antiretroviral triple therapy – a life-saving treatment for HIV/AIDS – became available. While access to therapy improved substantially in all groups over time, differences between blacks and whites in access to this therapy persisted throughout. Overall, HCSUS’ team of multi-disciplinary researchers from across the US produced high-impact papers in top-tier journals and hundreds of scientific publications altogether, to inform the research community, providers, and patient advocates. Equally important, the study’s findings also were used to guide a large roster of policy changes, including those pertaining to coverage of treatment and mechanisms to maintain vulnerable individuals on treatment, in order to reduce disparities in receipt of life-saving therapy and associated mortality disparities (Shapiro et al., 1999). Could there be differences in access to appropriate anti-epileptic drug treatment across disadvantaged groups for epilepsy? For multiple sclerosis? Without studies that measure to what extent such disparities exist and mechanistic research to elucidate what factors are associated with them, it is not possible to direct societal resources appropriately to interventions to reduce or eliminate disparities in health for these disorders.

## Emerging Findings in Genomics in Neurology and Health Disparities Research

The investment that NINDS is making in biomarker research to predict treatment response and in genomics are all exceedingly relevant to health disparities research. To successfully leverage these new research findings in translational research and genetics into improved population health, there must be a complementary body of research on behavioral and healthcare organizational factors influencing racial/ethnic disparities in access to these new genetic tests. As an example of the need for such research, a recent study by Shields and others (2008) from the Harvard/MGH Center on Genomics, Vulnerable Populations, and Health Disparities surveyed a large, national sample of primary care physicians. They found that those physicians' willingness to order genotyping tests in order to, "offer genetically-tailored treatments to their patients," (in their study, to individually tailor smoking cessation treatment) was significantly affected by whether the test was framed as genetic or non-genetic, whether there were racial differences in frequency of key risk alleles, and whether the same genotypes that would be used to tailor the therapy were also associated with psychiatric conditions (Shields et al., 2008).

### *c. Delineation of the different purposes of the disparities strategic plan; relationship to the Panel's recommendations*

Logically from the prior section, research that directly acquires new knowledge on what causes, and on interventions that are tested and shown to reduce disparities, is likely to have a large impact in society. Health outcome improvement through reduction in disparities is the common goal at the intersection of the NINDS mission and federal law/DHHS regulations. Ideally, relevant audiences for research on health disparities would use the findings (1) to shape policy-making (at the healthcare delivery system or at the local, state, or national government level); (2) to change behavior of the public and/or individuals affected by these disorders (for example, lifestyle behavior change); and (3) to change behavior of health professionals (for example, more effective elicitation of patient preferences around alternative approaches to management, through greater knowledge of specific cultural issues and better decision tools for clinical practice).

The NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology's final recommendation was that each NIH institute should include in their report each year not only research and research training dollars that are "targeted" at health disparities research questions, but also "non-targeted" clinical research and research training. The definition of non-targeted clinical research dollars that are counted toward both Minority Health and Health Disparities Research accounting are the, "percentage of the award based on the ratio of minority participants to total participants" (for studies exceeding a minimum of 25% minority participation). While some of this research may provide new knowledge that can be directly disseminated and used to reduce

racial and ethnic disparities in health, much or most of it is unlikely to have direct applications to policy or to patient or provider behavior change, based on review of titles of studies that are enumerated in Appendix B of the Panel's notebook.

Further, the panel found it noteworthy that in FY08, a total of 8 clinical research awards comprise the entirety of targeted health disparities research funded by NINDS at present, relative to nearly 300 studies identified as non-targeted clinical research. Dollar-wise, a little over 11 million dollars supports the 8 targeted studies, compared to a calculated 90 million dollars for the portions of the other 300 studies that are counted towards health disparities investment. This is a 9:1 ratio in non-targeted to targeted research dollars in the NINDS portfolio of what is designated as clinical research in health disparities (excluding training and outreach). While 300 studies would appear to be a laudable volume of clinical research studies that have enrolled or plan to enroll a sizeable minority component into the study sample, even a small increase in "targeted" research - studies that directly address what causes and how to intervene to redress health disparities for people affected by neurological disorders - could have an enormous impact on the yield of the institute's investment in producing new knowledge that can directly lead to reductions in health disparities. The FY 2008 investment in targeted clinical research in health disparities (excluding training and outreach) was approximately 0.7% of the entire FY08 NINDS budget.

While some general research on health disparities that is conducted elsewhere at NIH or in other agencies, such as AHRQ, NHLBI, and CDC, may yield findings that could apply to groups with neurologic disorders, there are several issues unique to people affected by neurologic disorders, and disparities research for other, non-neurological disorders may not be applicable or effective. One of these issues is stigma. Outside of mental health disorders, neurological disorders may be the most heavily stigmatized chronic conditions, and there is research to suggest that having a stigmatizing disorder and being in a disadvantaged minority population is a highly vulnerable context for which "standard" approaches may not be effective for overcoming disparities in access to or quality of care received. Second, neurologic disorders may often be of a nature that family caregivers or care partners need to be involved, as many of these diseases progress over time and may impair communication ability as well as cognition and mobility; the type of interventions that may be effective in improving quality of care with the addition of informal caregivers who may also be disadvantaged in terms of education, language concordance with providers, and wealth, is relatively unique (outside of dementia, where research is primarily supported through the National Institute on Aging). Finally, the process of championing research findings to push policy and promote behavior change by providers and patients requires time and effort.

National Healthcare Disparities Report: No Neurological Diseases Included

The 2009 National Healthcare Disparities Report issued by the AHRQ is mandated by Congress and is the seventh one that has been prepared by AHRQ and a DHHS-wide Interagency Work Group. The purpose of this comprehensive report is to enable tracking of how differences in healthcare delivery and outcomes due to disparities by race and socioeconomic status are changing over time. This important report includes metrics on quality and access to care and includes tracking of seven key conditions; none of these are neurological disorders.

*d. Analysis of formulation and impact of prior strategic plan*

In 2001 NINDS developed its first strategic plan in health disparities and then updated it in 2003 (NINDS OMHR, 2003). The Office of Minority Health and Research was charged with the development of the strategic plan. Implementation of its various components was described by Dr. Gordon at the in-person panel meeting in spring 2010 as moving from this office to the appropriate scientific cluster in which that disease or symptom was primarily associated, for development of RFAs and so forth.

Materials Reviewed

Across the two strategic planning efforts in 2001 and 2003, separate strategic plans were developed for a total of seven diseases or populations: stroke, HIV-associated neurological diseases, neurological complications of diabetes, chronic pain disorders, cognitive and emotional health of children, epilepsy and *status epilepticus*, and injury to the developing brain, plus three cross-cutting areas: research capacity building and training, dissemination of public information, and inclusion of minorities in clinical research.

Materials provided to the subcommittee included summaries of the 10 areas from the latest public version of the strategic plan (circa 2003), links to planning panel summaries for some of these, and a spreadsheet with a listing of planned activities in each of the ten focus areas, the outcome in terms of what happened with respect to that specific activity, and links to selected relevant materials (for example, a workshop summary or meeting report, a program announcement, a center website, others).

Priority-setting Process

There is no description of the criteria for selecting these ten areas, particularly the seven areas focused on diseases, symptoms, or subpopulations. The process of priority-setting did appear to include public review of documents and elicitation of comments at several points, but a record of the criteria for selection of the ten areas, the data that were synthesized relevant to those criteria, and the process of deliberation and selection are not described. On the surface, several high volume conditions appear to have been prioritized – certainly stroke, epilepsy, and neurologic complications of diabetes. However, within those selected conditions, there is no information evident about how different goals or

activities were selected as high-priority targets. For example, was it judged that stroke prevention needed more research on mechanisms of disparities or was ready for interventions to be developed and tested? The report of the 2002 Epilepsy Disparities Planning Panel (National Institute of Neurological Disorders and Stroke, 2002) stated that the panel recommended research to acquire evidence on the extent of the problem and mechanisms, but the only RFA released in response to this report requested studies on interventions. Six applications were received and none funded; but the RFA was asking for proposals addressing a stage of disparities research that may not have been ready for proposals on interventions, because the research on levels of disparities in epilepsy care and outcomes - and the factors and contexts in which they occurred - had not yet been done.

### Evaluation Measures

The most updated version that is described as, “the latest plan that was made publicly available,” appears to be from 2003. It is not clear who is charged with evaluating the impact of the strategic plan activities, or if there is any internal procedure within NINDS for back-and-forth feedback on implementation of the strategic plan. (If there were, one would anticipate updates or new activities in the last six years, but the most recent listed start date for any activity outside of stroke is 2004). Are activities in the plan reviewed annually, and progress relative to benchmarks assessed? If so, by whom is this done and with who is it shared? How are revisions to the implementation of the plan made?

The indicators that are described for performance measures in the plan are sometimes very non-specific (“establishment of the necessary structure to support the above lines of research...”), or are stated in terms of a measure (number of NINDS publications translated into Spanish) but not a target (like how many publications or what proportion would be the ideal goal?). Some of the performance measures are specific (“development and release of Program Announcements (PAs)/RFAs targeted on the priority area”), but the most distal ‘outcome’ described for any performance measure is the number of applications funded on that topic; there is no distillation of the yield of new knowledge acquired or to-be-acquired, or its projected impact on differences in health across racial/ethnic groups with the particular disorder.

### Review of Summary of NINDS Health Disparities Strategic Plan and Outcomes

A spreadsheet in Section IIID of the panel notebook lists for each of the ten areas an activity, its objective, year initiated, and what happened out of that activity. Key implementation and outcome features tallied from those spreadsheet data are summarized below:

<b>Area</b>	<b># of activities acted on/# of activities</b>	<b>Year of Most Recent Activity Start</b>	<b>Any PAs/ RFAs ever released</b>	<b>Any grants ever funded by NINDS</b>
Stroke	7/7	2007	Yes	Yes but not from PA, but via 2 SPIRPs
HIV-neuro	4/5*	2001	Yes	Yes via SNRP
Diabetes-neuro	2/6*	2002	Yes	No
Pain	3/4	2003	Yes	Yes but only 3 of 73 routed to NINDS were funded & on disparities
Cognitive/emotional health-peds	4/7	2003	Yes	No
Epilepsy	2/5	2003	Yes	No
Peds TBI	0/2	2003 <sup>^</sup>	No	No
Research Capacity	11/11*	2003	Yes	Yes
Dissemination and Outreach	5/5	2004	n/a	n/a
Minority inclusion in clinical research	0/1	Not begun	n/a	n/a

\*some activities have start dates listed as years before the strategic plan

<sup>^</sup>held workshop in 2008 but unclear if arose from strategic plan



Notable findings are:

- The only 3 areas where all planned activities were acted on were research capacity, dissemination and outreach, and stroke.
- One or more PAs or RFAs were released for 6 of the 7 disease or symptom areas, but over seven years, only 3 proposals (all in pain) were funded by NINDS out of any of the PAs or RFAs, except for Stroke Program/Intervention Research Program (SPIRP) and Specialized Neuroscience Research Program (SNRP) mechanisms.
- As noted above, the start date of the most recent activity that was initiated across nine areas (excluding stroke) was 2004

In summary, the prior strategic plan for health disparities at NINDS could have had greater impact if it had a dynamic process of review, adjustment, and follow-through on implementation. The priority-setting criteria are not specified, and the outcomes in terms of new scientific knowledge are unlikely to be extensive, given the relatively small output of intermediate outcomes such as studies funded in response to announcements.

#### Examples/"Best Practices" from Other ICs

The panel reviewed reports from selected other institutes available through *Sharepoint* links, including those of NCI, NHLBI, NIDDK, NIMH, and NIAMS. These also date to 2002-2003, and we did not examine other sources for comprehensive updates, although staff did provide brief summaries of several other institutes' more recent descriptions of their staffing and ongoing efforts in health disparities. Of the older reports, it is notable that like NINDS, most also only describe their outcomes in terms of funded studies or even more non-specifically, with the exception of NHLBI: NHLBI provided a paragraph under outcomes summarizing key publications in high-impact journals and brief synopses of the findings and their implications. At a minimum, this is a model that enables Institute leadership to assess an outcome that is closer to estimating potential impact on reduction in a health disparity. NIMH described its priority-setting process in more detail, and included ranking of the objectives. The National Cancer Institute (NCI) appeared to be the only institute reporting (at that time) a calculator to enable estimation of the extent of disparities from SEER (Surveillance, Epidemiology and End Results program) data.

## IV. Further Discussion and Suggestions from Content Areas

### *a. Vision, strategic plan and priorities*

An important consideration for a NINDS health disparities research office is the development of a priority-setting process. The priority-setting process for health disparities research should be data-driven, standardized, transparent, and bring to the table a range of perspectives. Data-driven means judicious use of systematic literature reviews. The process should include public comment; standardization means use of formal, scientific methods for optimizing judgments, to rank research priorities. Priority-setting of any kind is not static or once-in-a-decade, but ideally should be updated/re-assessed – at least components – annually by NINDS. It will require a change in the current procedure and “culture” to do this.

#### A Priority-setting Process for Health Disparities Research Has Three Stages:

1. *Identify for further consideration those conditions with high overall burden of disease and for which there are potentially unique issues due to the nature of the neurologic condition.* NINDS is relatively unique among NIH institutes in that its mission encompasses hundreds of diseases. Thus, one of the two most important initial considerations for identifying diseases or subpopulations with neurologic disease for priority-setting for health disparities research is: how large are the population projections of the potential health disparities or differences? A second major factor for prioritizing conditions or subpopulations is: what are the potentially unique aspects of racial/ethnic disparities in health for persons with particular neurologic conditions? That is, for which conditions can we not assume that knowledge about interventions effective for non-neurologic conditions is applicable to neurologic conditions. For example, the stigma associated with epilepsy may create racial or ethnic barriers to recognition of the disease and receipt of high quality care for which interventions known to be effective for certain non-neurologic conditions cannot be assumed effective for persons with epilepsy from disadvantaged racial/ethnic or socioeconomic groups.
2. *Analyze (through asset mapping or other formal analyses) what other ICs, Federal agencies, non-profits, or other organizations are doing to address the problem for the high priority populations identified.* The purposes of this step are to learn ‘best practices’ from other organizations that are tackling a similar issue (for example, NHLBI outcomes research centers addressing disparities in risk factor control), to avoid duplication of effort and possibly introduce efficiencies in investment of resources through partnerships, and to increase the likelihood that the new knowledge that is generated will be used to effect change that will redress health disparities.

3. *Match the levers employed to the stage of unmet need for knowledge about health disparities for that condition or subpopulation.* For example, if what is needed is knowledge about the causes of well-documented racial/ethnic disparities in health for people with a given condition, then research should be facilitated that will generate new knowledge on mechanisms, rather than facilitating research on interventions or on surveillance. The four stages of health disparities research are:

*I. Surveillance* - What is the magnitude of disparities in health for the condition or subpopulation? Do any exist? If so, is the magnitude or uniqueness of occurrence in that condition or subpopulation sufficient to warrant investment in mechanistic research?

*II. Mechanistic* - For conditions or subpopulations identified in stage I, what are the factors (biological, social or environmental) that explain the disparities, focusing in particular on those that have the potential for modification through individual, provider, healthcare delivery system, neighborhood, or policy change?

*III. Intervention Design and Testing* - Once a body of explanatory knowledge is sufficient to inform intervention strategies, research is needed to provide evidence as to what behavioral, clinical or policy interventions work.

*IV. Dissemination/Translation of Evidence* - Once successful interventions have been identified, what strategies are effective for widespread uptake of those interventions? Note: Some effort at this stage will be focused on research, but some of the effort for this stage may be to disseminate findings generated in prior stages to relevant policy and administrator audiences, as well as dissemination to the public and to professional societies.

### Suggestions

1. Establish a health disparities office that contains at least one health services researcher with experience in health disparities research.
2. Establish “go-to” people in each cluster for the health disparities office to get help with advising potential grantees in the broad areas covered by NINDS.
3. Identify and provide background data to support a list of the 8-10 most common neurologic diseases (for example stroke, epilepsy) or subpopulations (for example, adults or children with chronic neurological disability) through an internal cross-cutting group (with representatives from each cluster, Office of Clinical Research, Office of Science Policy and Planning, and Office of Minority Health and Research), and vet this list through review by NINDS and possibly public comment.

4. Identify existing systematic literature reviews on current knowledge about health disparities, and commission reviews where no systematic reviews exist, for all diseases/subpopulations on this list.
5. Identify an internal working group to work closely with and hire a contractor to conduct an asset map or other analogous analysis of which organizations and agencies (both in and out of government, local to national; and by region, if applicable) are currently engaged in research or dissemination efforts to address disparities for any of the high priority conditions; incorporate existing NINDS efforts into the analysis.
6. Hold a workshop with external and internal scientists and representatives from stakeholder organizations to make and rank recommendations for priority-setting areas and collaboration with other ICs, agencies, and organizations based on (1) the level of evidence for whether significant racial/ethnic disparities exist across the selected diseases and subpopulations (from the systematic reviews and other sources), (2) the stage of health disparities research (I to IV) where new knowledge is needed (where applicable), (3) and the asset map analysis of ongoing efforts and resources. Ask for public comments on the report and recommendations.
7. Document in writing the priority-setting process and subsequent annual updates and revisions, and their rationale.
8. While the priority-setting process is underway, review new and ongoing disease-specific initiatives within NINDS for incorporation of activities in health disparities research, for example, the Epilepsy Centers without Walls, the Udall Centers, and others.

*b. Organizational structure, scope, and collaborations*

Background

The Office of Minority Health and Research (OMHR) within NINDS, established in 1998, is primarily responsible for special programs, specific grants and fellowships involving health disparities research. The organizational structure of OMHR consists of three program directors and a program specialist working in close proximity. OMHR staff-members are deployed around the nation carrying a message of NINDS priorities, particularly at scientific conferences.

However, based on information provided to the committee, it appears that health disparities research is sparse, and what little there is spreads throughout NINDS across Offices and Clusters, and the role that OMHR plays in designing initiatives and fostering programs in health disparities research is extremely limited. Health disparities research projects are not housed in a single silo, i.e. they are principally associated with scientific topic. OMHR seems to be mainly involved in efforts targeting the creation of diversity in the workforce and clinical trial populations. There is no discernible systematic approach towards originating or managing health disparities research at OMHR or Institute-wide. Although there are some important large epidemiological and health behavior studies (U-awards) geared at understanding and remedying the basis of health disparities (at OMHR, OCR), these are clearly too few.

Historically it seems that as concerns about health disparities rose, NINDS took advantage of the available SNRP to rapidly initiate programs in underserved communities that did not have major epidemiological expertise. However SNRPs were originally designed to diversify the workforce and facilitate the successful transition into R01-funded research in any scientific area. There are relatively few partnerships in collaborations with other NIH institutes (Hispanic Community Health Study is the only example seen), academia, industry, patient advocacy, and other Federal agencies with regard to developing health disparities research and moving the field forward.

### Suggestions

9. Make HDR more focused and accountable with targeted goals, metrics and missions. Specific expertise is needed for this area, and there are several activities/opportunities occurring across NINDS, NIH, other Federal Agencies, etc., but no one to track them and facilitate potential collaborations.

There are two potential avenues for doing this:

- Create a position of Program Director for health disparities research within OMHR. This person will be responsible for driving and coordinating all health disparities research at NINDS. This option could be advantageous because it should not involve a lot of capital, will permit close interactions with current OMHR personnel, and will still allow distribution of health disparities research within Clusters which currently permits an investigator to remain plugged into the relevant community for that area of neurology. However, with this option, consideration should be given to changing the name to “Office of Minority Health and Special Populations Research” to accommodate all forms of health disparities research (e.g. including women, rural populations, individuals with disabilities, the very elderly, etc.)

- Establish a new distinct office for health disparities research at NINDS, whose leader will report directly to the Director. *We strongly endorse this avenue.* This option would ensure that health disparities research does not inadvertently get lower priority to workforce diversity. Two other institutes (NCI, NIMH) have dedicated Offices for health disparities research. However, the NIMH Office also engages in global health research (The NIMH Office has a Director, two Deputy Directors, a Program Chief, 1 Program Director, 4 Analysts, a Program Specialist and a Program Manager). This latter approach of combining health disparities research and global health research could be advantageous to NINDS because these two important yet not unrelated areas could be tackled together leveraging the same personnel/resources and ensuring that neurological diseases receive adequate health disparities research and Global Health focus. In addition, an “Office of Research on Disparities and International Health” could readily incorporate three of the NIH Director’s “themes” (biology {genetics}, health care reform and global health) and provide opportunities to jointly promote/fund studies examining the biological basis for race-ethnic health disparities.

10. Establish Scope of Dedicated Program or Office.

- Properly define health disparities research and establish scope/goals within NINDS. This will also help with appropriately assigning codes to projects deemed to fall under health disparities research. In particular health services research needs greater prominence.
- Increase submissions of unsolicited R01s on health disparities research by hosting a regular series of workshops to bring potential investigators together that will submit such applications. The dedicated health disparities research Program or Office will arrange these workshops but involve all NINDS Clusters.

11. *Collaborations.* Growth of this area could be a particularly effective way to capitalize on shared interests, and to leverage limited resources, and avoid redundancy.

- Important direct NIH partnerships would be a) NINDS Clusters, b) NIMHD, c) Other ICs and government agencies (AHRQ, NHLBI, etc.). A main objective would be to make all NINDS personnel doing HDR aware of what’s happening both in NIH and other places within DHHS (e.g., CDC), as well as in NGOs that do health disparities research, so that everybody is fully aware of health disparities research activities/opportunities (with potential relevance to the NINDS mission), and that there is an ability to establish (and maintain) collaborations.

- NINDS HDR personnel should be more visible at relevant Scientific Meetings and sit on appropriate Committees of the various Scientific Groups and Non-Governmental organizations as much as possible.
- Collaborations with health disparities research advocacy groups given their perspectives on quality of life issues embedded in the NINDS mission. This could provide opportunities for matching grants for small studies or co-sponsoring workshops (conduits through which the communities could provide relevant input into the program and initiative development).

### *c. Evaluation and accountability*

#### Background

There is little evidence of an ongoing procedure to track and evaluate the success of health disparities research efforts at NINDS. A structured approach to track and evaluate the success of health disparities research initiatives is very much needed to determine effective use of resources.

#### Suggestions

12. Clearly defined metrics of success and impact are needed. The panel feels these should include: RFAs launched, responses to RFAs, funded applications, papers produced from funded research, new investigators funded in the health disparities field, and findings of relevance to policy-makers, clinicians and patients/patient advocate as the primary metrics. Very specific metrics within each area should be defined.
13. To the degree that population-based surveillance data are available on the metrics of health disparities for neurologic conditions, monitor these data to determine if NINDS-targeted areas of disparities research show evidence of meeting the needs of the communities that are affected. Identify and support opportunities to collaborate with agencies such as the CDC to expand the ascertainment of selected surveillance data.
14. These metrics should be developed through a transparent process with both internal and external advice and with input and approval by Council. A full process of development should occur every three years with yearly updates.

15. The health disparities research office should be accountable to the NINDS Director with respect to progress on achieving the defined goals and provide annual reports to NINDS Council for advisory feedback as well. Yearly adjustments should be made as needed to accomplish the set targets.

#### *d. Training in health disparities research*

##### Background

In order to reduce the burden of health and healthcare disparities in the neurologic population, we first need to build the research capacity to address this issue. A critical component of this increased research capacity will be the training of high quality health disparities investigators. These investigators will require research support, a unique research skill set, a multi-disciplinary research environment and experienced mentorship to be successful.

Training opportunities specific to health disparities research do not currently exist within the NINDS. During the years 2004 to 2009, the NINDS funded a total of 1,493 career development awards (K01, K02, K08, K12, K23, K24, K99), 2,409 fellowship awards (F series) and 449 training grants (T series). However, only 13 of these awards (all K's) involved health disparities research. This translates to less than 0.30% of all career and training awards. A targeted, more intense effort to train health disparities researchers is needed.

##### Suggestions

16. Set training in health disparities research in basic and clinical neuroscience as a high NINDS priority.
17. Create an additional role for an NINDS staff member knowledgeable about health disparities research and training opportunities. This staff person's responsibilities will be to: organize and implement training opportunities, promote health disparities research training applications, educate existing NINDS staff on health disparities research training priorities, and evaluate the success of any health disparities training program.
18. Utilize existing training mechanisms in basic, translational and clinical science – Pre-doctoral and Post-doctoral Fellowships (F31, F32), Mentored Career Development Awards (K01, K08, K23, K25, K99/R00), Independent Scientist Awards (K02, K24,



R15) and Institutional Training Programs (T32, K12, R25) – to train both early and mid-career investigators in health disparities research.

19. To increase the number of successfully funded applications in health disparities research, we recommend that the NINDS issue an NIH Guide Notice on the NIH Parent Announcement(s) to announce that health disparities research is of particular interest to the institute. Thus, applications in health disparities research will be identified and prioritized for funding during the internal review process.
20. Select grant reviewers with expertise in health disparities research to relevant study sections to appropriately and fairly review training applications.
21. Establish a new Program Announcement (PA) for a Mentored Career Development Award (K) in Health Disparities Research in basic and clinical Neuroscience to signal that the training of junior investigators dedicated to a career in health disparities research in neuroscience is an area of increased priority for the NINDS and encourage junior investigators to pursue a career in health disparities research.
22. Collaborate across institutes and centers to:
  - Combine resources to accomplish shared goal. For example, the mission of the National Institute on Minority Health and Health Disparities (NIMHD) is to promote minority health and reduce health disparities. The NIMHD sponsors a 2-week course, “Integrating principles of science, practice and policy in health disparities research.” The NINDS could co-sponsor with the NIMHD a similar, but abbreviated course focused on neuroscience. Selected NINDS staff should attend the current NIMHD course.
  - Capitalize on established mentorship and experience in health disparities research from existing senior investigators. For example, the NIA funded Resource Centers for Minority Aging Research (RCMAR) provide research infrastructure, fund pilot projects, mentor investigators toward R01 funding and conduct seminars and conferences for junior investigators in health disparities research at 6 centers across the country. The NINDS could provide funding for the training of an additional investigator interested in neurological diseases.
23. Convene a workshop to determine the content and structure for appropriate training of investigators considering a career in health disparities research.
24. Sponsor an annual course or workshop for young investigators interested in health disparities in Neuroscience to provide an overview of research methodology and

ongoing health disparities research and details about NIH grant process. Alternatively, this material can be incorporated into existing courses, e.g., Clinical Trial Methodology Course in Neurology, or the NINDS can consider co-sponsoring a similar workshop with other institutes, e.g., the 2009 NIH Summer Institute on Community-Based Participatory Research Targeting the Medically Underserved sponsored by the NIH, Office of Behavioral and Social Science Research, NCI, National Institute on Drug Abuse (NIDA) and National Institute on Environmental Health Sciences (NIEHS).

25. Develop a set of metrics to evaluate the success of training programs in health disparities research, and annually evaluate all training initiatives.

*e. Recruitment, enrollment and retention in clinical trials*

Background

It is increasingly realized that the incidence, pathophysiology and complications of diseases are variable in different human populations. The effects of treatment are also variable in these populations. Hence studies performed in majority populations may not be generalizable to all populations. The recruitment of minority populations and underrepresented minorities pose unique challenges. Data suggest that while some improvements in recent years have occurred in recruitment of women and African American populations in NIH funded clinical trials, recruitment of Hispanics continues to be difficult, and comparable data on Native American and Asian populations is not available. The strategies for recruitment of these populations are different from those of majority populations and may require more effort to address concerns. Community based approaches and development of an element of trust are crucial. Hence it would be important to empower researchers with the information necessary to improve and maximize recruitment of these populations in clinical studies. Further, monitoring the recruitment success at each level of research may be necessary.

Suggestions

26. *Training.* Provide a training module to researchers and their project management staff on effective strategies on recruitment of these populations. The training could be provided in different ways. For example, a web based module could be added to the existing human ethics course that is a requirement for all researchers to take prior to receiving funding from NIH. Other possibilities include targeted seminars and workshops, which can be included in other institutional grants that include a

training aspect supported by NINDS, such as T32s, center grants, Clinical and Translational Science Awards (CTSAs), etc.

27. *Grant Review.* Current NIH grant review process does not include the human subjects section to be considered as part of the scoring process. Including this in the final scoring would greatly increase the impact and importance of recruitment of the subjects to clinical studies, although we realize this would require an NIH-wide policy change. The current human subjects section requires a breakdown in tabular form on the populations that will be recruited to the clinical study. A section on how the researchers plan to recruit these populations would be very helpful, since it will force the researchers to think of strategies to enhance recruitment of these populations. An alternate suggestion is to try to enforce the existing policy for minority recruitment and retention and request that the reviewers comment on these plans so that the Scientific Review Officer would follow up on the reviewers' recommendations and the grant would be awarded only when those concerns have been adequately addressed.
28. *Progress Reports.* In progress reports, the researchers should be required to not only provide information on the populations recruited but if they have been unsuccessful in achieving their goals for recruitment of these targeted populations to provide explanations for the reasons, and to provide a plan to remedy the issue. It is advised that the program officers review each publication in the yearly progress report to see if data on gender and minorities has been provided and analyzed. Analogously, for those researchers who had minority recruitment and/or retention strategies that were successful, a description of what they thought was effective and any tips on key contextual factors or on how to implement those strategies should also be required in the progress report. These summaries should be made into a searchable online compendium that is publicly accessible and/or included as part of the reporter system.
29. Final progress reports to NINDS should include analysis of the clinical study that breaks down the effects by each of the minority populations and underrepresented minorities.
30. *Publications in Journals.* We suggest that NINDS consider encouraging scientific journals that publish clinical research on neurological diseases, to include information on the minority populations and underrepresented groups in the methods section and where possible to present analysis of data on these groups. These journals may also be encouraged to publish in a supplement the methods used to recruit and retain these minority populations. NINDS may also consider

combining efforts with other institutes to influence the International Committee of Journal Editors on this issue.

*f. Community education and dissemination of health disparities research findings to healthcare professionals and to policy-makers*

Background

Is community outreach worth the effort and expense? The answer is a resounding yes. The need to reach at-risk populations with information garnered from NINDS-funded research is huge. With an ultimate goal of improving health outcomes in underserved minority communities, the potential exists to a) encourage healthier lifestyles, b) foster a prevention mentality, c) develop role models not only for at-risk adults but for younger generations, and d) empower individuals to gain greater control over their own health. In the process, the opportunity exists to increase public understanding of the role of NINDS and its activities. Additional benefits of a powerful community outreach program will also be felt in the areas of NINDS health disparities training and clinical trial promotion.

NINDS has had public education programs for minority populations in place for several years. So some of the following suggestions/recommendations, particularly those related to audience and communications research, have almost certainly been followed in the past. However, it is important to revisit these issues on a regular basis to ensure that programs/campaigns/strategies remain focused and on point.

Also, while it is practical to refer to particular racial/ethnic groups in umbrella terms (e.g., Hispanic or Latino), we should always remember that within those groups lay multiple sub-groups (e.g., Mexican Americans, Cubans, Puerto Ricans, South and Central Americans) with very different characteristics, backgrounds, preferences, attitudes and behaviors, etc. To be effective, community outreach programs must always keep these differences in mind.

Suggestions

31. Define your audience(s). The term “minorities” is obviously much too broad. Before a community relations plan can be conceptualized and implemented, it is essential to identify the specific groups you want to reach with your message(s). This begins with, for example, African Americans, Latinos and Native Americans. It continues with identifying the at-risk elements of those groups, including specific gender and age groups. Subsequent approaches and strategies will ultimately be shaped by the

specific audiences you are attempting to reach.

32. Research your audience(s) and relevant health communications. Awareness of what has been learned over the years begins with a search of the scientific literature and examination of what other institutions and entities are doing with regard to community outreach for minority populations. For each of your audiences, it is important to know:
- The channels of communication (e.g., mass media, Internet, print materials, person-to-person)
  - The various venues for communicating with target groups (e.g., home, workplace, clinics, schools, churches, businesses)
  - Preferred information communication means (e.g., television, radio, newspapers, Internet)
  - How individuals currently receive health information (e.g., media, physicians and staffs, Internet, family, friends)
33. *Assess current/previous NINDS public education efforts.* Over the past decade, NINDS has worked to improve communication of health issues with minority audiences. Efforts have included developing radio public service announcements (PSAs) targeting African Americans and Latinos, organizing media tours with experts trained in culturally appropriate talking points, targeting at-risk communities with the *Know Stroke* campaign, and creating a considerably stronger Spanish-language Web presence. Goals of previous NINDS strategic plans have also included expanding the information network, dissemination of medical news/information to the public, and development of new communication outlets (National Institute of Neurological Disorders and Stroke, 2009). It is very important to assess the effectiveness of these efforts, and continue and expand those deemed most worthy. It is also important to understand the process by which NINDS messages, materials and campaigns are selected, developed, vetted, tested and evaluated. In addition, it would be very helpful to learn how communications teams work with NINDS disparities researchers, particularly those conducting behavioral research, as outreach strategists develop their communications plans for underserved communities.
34. *Prioritize needs and goals.* Of course, funds for developing and expanding community relations programs are not unlimited. Therefore, it is important to determine priorities in terms of health issues to be addressed and audiences to be targeted, which requires development of clear and methodical prioritization processes and procedures. To maximize the impact of education strategies, a focused approach is always preferable to “shotgun” efforts.

35. *Employ sound scientific principles.* Every step and every aspect of community outreach should be driven by research. This of course includes audience identification, health issue focus, concept and message development, approaches and strategies to be employed, and means of message delivery. Methodologies should be evidence-based and employ proven scientific practices and theory. This does not preclude innovation and creativity – indeed, these are valued assets in finding the most effective means of reaching the target audiences. However, testing of concepts and messages with the specific audiences is essential. This is the only way to ascertain if and confirm that the elements of a program are culturally sensitive, relevant and appropriate. In addition, sound evaluation principles should always be present.
36. *Specific areas to explore -- NINDS disparity research.* A small but important nidus of previous and current neurological research has included a focus on reducing the burden of neurological disease in minority populations and improving access to and dissemination of research information to the public. It would be prudent to consult investigators who have been actively involved in this health disparities research in recent years. It is important to ascertain or confirm the lessons learned by these researchers, and to incorporate these findings into approaches and strategies that can enrich the community outreach program going forward. Other sources of information include publications, grant applications (including reviewer critiques), the PubMed Central database and other newer tools such as NIH SPIRES for tracking publications and grant data.
37. It is important that research findings not only be published in journals but be operationalized in processes leading to elimination of health disparities. With this goal in mind, methods should be explored to strengthen efforts to disseminate NINDS-funded research findings on health disparities and to give thought to ways this information can and should be used. For example, the NCI requires its awardees to include a community education component in some clinical research grants. Moreover, NINDS should consider focusing attention not only on the community but other audiences, as well. Such audiences include groups instrumental in making changes that will translate these findings into reduced health disparities for individuals with neurologic diseases (audiences such as policy-makers at the national, state, and local levels; health care plan administrators; and professional societies who educate a range of health care workers including but not limited to neurologists). For example, findings from a trial of care management for stroke secondary prevention in the public safety net system should not only involve

community outreach but also dissemination to the national network of public safety net health care administrators.

38. *Partnerships.* Opportunities no doubt exist to join forces with other institutes, nonprofit organizations and other entities (particularly health-related – e.g., those focusing on cancer, heart disease, diabetes and AIDS) endeavoring to reach the same racial/ethnic minority populations. For many of these entities, the disease prevention goals are essentially the same: to eat healthfully, exercise regularly, stop smoking, reduce alcohol consumption, etc. The pooled resources of partnerships enable parties to expand and strengthen efforts and common/similar objectives. In addition, the dissemination of NINDS health disparities research findings presents further opportunities for developing and/or expanding partnerships both within the Institute (e.g., both the Office of Communications and Public Liaison and the Office of Science Policy and Planning, seeking out the broader range of audiences discussed in no. 36 above) and outside (e.g., agencies such as the Health Resources and Services Administration (HRSA) and CDC, and community health groups).
39. *Piggyback opportunities.* Hand-in-hand with the potential for partnerships are the opportunities to “piggyback” on existing health promotion campaigns in communities. For example, in several cities across the United States with heavy concentrations of Latinos, the *Salud En Acción* cancer education program recruited community volunteers called *promotoras* to disseminate literature and promote screening and other healthy behaviors among Latinos. The program's model, based on sound scientific theory and principles (e.g., Social Cognitive Theory), provides an appropriate public education vehicle for delivering messages related to virtually any health condition of relevance to the Latino population. For NINDS, excellent opportunities exist to piggyback on programs such as *Salud En Acción* that have achieved significant success and partner with the sponsoring entity to include messages and materials focused on stroke and neurological disorders related to diabetes and AIDS.
40. *New technologies.* In recent years, all population groups have increasingly adopted a wide variety of communication tools spawned by various technological advances. The computer, the Internet, and cell phones and other hand-held communication and information-gathering devices have become commonplace in today's society. More and more, information is being relayed via social media avenues, such as Facebook, Twitter and YouTube. All health entities, including NINDS, would be well advised to consider incorporating these and/or other technology-based communication channels in their current and future public education campaigns.

41. *Innovative approaches.* In the world of community outreach, ideas and concepts are myriad. For example, consider the possibilities if multiple health-oriented entities partnered to develop “community prevention centers,” where individuals, families and schoolchildren could view exhibits and videos, hear lectures, obtain literature and audio/video tapes, watch and perform in skits, and much more. Local volunteers and role models could be recruited to represent the prevention center as ambassadors in the community. Perhaps these centers could develop video productions to be looped onto monitors where available in waiting rooms at doctors' offices and clinics. The potential for creative and enterprising offshoots is large.
  
42. Partnering with other institutes, other branches of DHHS (including CDC), and NGOs involved in providing health messages to minority populations and disseminating research findings on new knowledge about how to redress disparities in health for persons with neurological conditions is crucial. Adding NINDS messages to existing external efforts of partners may provide an efficient way to use resources to inform, educate and motivate the public, healthcare professionals and administrators, and policy-makers about NINDS research findings on health disparities.



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