James P. Scanlan Attorney at Law 1529 Wisconsin Avenue, NW Washington, D.C. 20007 (202) 338-9224 jps@jpscanlan.com

June 1, 2010

Harvey V. Fineberg, M.D., Ph.D.
President
Institute of Medicine
National Academy of Sciences
National Academy of Sciences Building
2101 Constitution Ave., NW.
Washington, DC 20007

Re: Role of the Institute of Medicine in Guiding Health Disparities Research

Dear Dr. Fineberg:

From time to time, the Institute of Medicine (IOM) has endeavored to provide guidance for research into health and healthcare disparities. The most recent example of IOM's efforts in this regard is the April 24, 2010 document *Future Directions of the National Healthcare Quality and Disparities Report*. But the IOM's contribution in this area has been a questionable one in light of its failure to identify and address certain crucial measurement issues.

Disparities in health and healthcare are generally evaluated in terms of some standard measure of differences between outcome rates – mainly, relative differences in experiencing an adverse or favorable outcome, absolute differences between outcome rates, and odds ratios, as well as various more complex measures that are in some way functions of the measures just mentioned. Virtually all health disparities research, however, has failed to consider certain patterns whereby, solely for reasons related to features of the underlying risk distributions, each standard measure of difference between outcome rates tends to be systematically affected by the overall prevalence of an outcome. The most notable of these patterns is that whereby the rarer an outcome, the greater tends to be the relative difference in experiencing it and the smaller tends to be the relative difference in failing to experience it. Thus, as mortality declines, relative differences in mortality rates tend to increase while relative differences in survival rates tend to decrease. As beneficial procedures like mammography and immunization become more widely available, relative differences in receiving them tend to decrease while relative differences in failing to receive them tend to increase. Absolute differences between rates and odds ratios tend also to change systematically as the overall prevalence of an outcome changes, though in more complicated ways. Roughly, as uncommon outcomes (those with rates of less than 50% for both groups) become more common, absolute differences between rates tend to increase; as common

Harvey V. Fineberg, M.D., Ph.D. President Institute of Medicine June 1, 2010 Page 2

outcomes (those with rates of more than 50% for both groups) become even more common, absolute differences tend to decrease. Differences measured by odds ratios tend to change in the opposite direction of absolute differences between rates.

The point is not simply that one may draw different conclusions depending on choice of measure. Rather, the point is that to draw meaningful conclusions about the size of health or healthcare disparities, including whether such disparities are increasing or decreasing over time, one needs to distinguish between patterns that are functions of differences in the overall prevalence of an outcome and those that reflect something more significant.

Over a hundred references explaining the above-described patterns as they bear on the interpretation of group differences in the law and the social and medical sciences may be found on the Measuring Health Disparities ¹ (MHD) page of jpscanlan.com, and the nuances of the patterns are discussed on the Scanlan's Rule page of the same site. See also the Mortality and Survival page, which addresses the way that, especially in cancer journals, researchers discuss disparities in mortality and disparities in survival interchangeably without recognizing that the two disparities tend to change in opposite directions. The Solutions sub-page of MHD addresses an approach to measuring differences between outcome rates that is not affected by the overall prevalence of an outcome and the Solutions Database sub-page of MHD provides a downloadable database with which to implement that approach. A number of key references are found after the signature.

The extent of scholarly consensus with the views described above is summarized in <u>Section E.7</u> of MHD. That section shows that in Europe, where considerably greater thought has been given to these issues in than in the United States, there appears to be an emerging recognition among leading epidemiologists that there exist systematic relationships between standard measures of differences between outcome rates and the overall prevalence of an outcome and that researchers cannot interpret such measures without consideration of the role of overall prevalence. While such recognition has not yet had a significant impact on the way health and healthcare disparities are studied in Europe, such impact ought not to be too many years away.

Meanwhile, as shown in the same section, in the United States, particularly among the government agencies most responsible for guiding research in this area, these issues have been almost entirely ignored. For example, after reference 2 had pointed out that, because appropriate health care rates were increasing, healthcare disparities (measured in terms of relative differences in receipt of appropriate healthcare) were perceived to be decreasing, the National Center for Health Statistics (NCHS) simply responded by recommending that all health and healthcare disparities be measured in terms of relative differences in adverse outcomes. This recommendation tended to ordain that healthcare disparities previously deemed to be decreasing

¹ The underlining of various references in this letter reflects the fact that, in order to facilitate review of those references, links to the references are provided in an electronic copy of this letter posted on the Institutional Correspondence sub-page of the Measuring Health Disparities page of jpscanlan.com.

Harvey V. Fineberg, M.D., Ph.D. President Institute of Medicine June 1, 2010 Page 3

now would be perceived to be increasing. But the agency did nothing to address the critical issue of the development of a means of measuring disparities in a way that is unaffected by the overall prevalence of an outcome. As discussed in reference 5, the Agency for Healthcare Research and Quality (AHRQ) measure disparities in terms of whichever relative difference (in the favorable outcome or the adverse outcome) is larger. Thus, AHRQ sometimes reaches the same conclusions as NCHS and sometimes reaches opposite conclusions from NCHS.

Reference 6 provides a particularly useful illustration of the issues. It comments on a 2008 *Pediatrics* study for which the Robert Wood Johnson Foundation presented the principal author (Dr. July Morita of the Chicago Department of Public Health) an award for addressing health disparities. The study examined the effects of a school-entry Hepatitis B vaccination requirement on racial and ethnic disparities in vaccination rates among Chicago school children. Dr. Morita and her colleagues, relying on relative differences in vaccination rates as a measure of disparity, found that the requirement dramatically reduced racial and ethnic disparities in vaccination rates. But the NCHS would have found dramatic increases in disparities. And AHRQ would have reached different conclusions as to directions of change for different time periods. Researchers who rely on absolute differences between rates would also have reached different conclusions as to the direction of change for different time periods, which conclusions would be the opposite of those reached by AHRQ.

I urge you and your staff to review the referenced materials, especially reference 5, the 2007 American Public Health Association conference presentation on measurement problems in the National Healthcare Disparities Report, and consider whether that report can actually provide anything of value until AHRQ addresses the measurement issues. Further with regard to the practices of AHRQ, it warrants note that AHRQ funds a great deal of healthcare disparities research without any apparent thought to the manner in which researchers measures disparities. As it happens, a good deal of AHRQ-funded research analyzes disparities in terms of absolute differences between outcome rates. Given that absolute differences between outcome rates tend to change in a pattern that is the opposite of the pattern exhibited by the larger relative differences, there exists a tendency for this research to systematically reach conclusions that are the opposite of the conclusions AHRQ would reach.

Finally, while I bring these issues to your attention with respect to IOM's role in guiding the National Healthcare Disparities Report and other health disparities research, the issues raised about measuring health disparities apply to a wide range of medical and epidemiological issues, as discussed, for example, on the Measures of Association page and the Subgroup Effects and Illogical Premises sub-pages of the Scanlan's Rule page. Thus, the referenced materials bear on aspects of IOM's functions apart from guiding health disparities research.

² See also the <u>NHDR Technical Issues</u> sub-page of MHD, which addresses certain technical problems with the National Healthcare Disparities Report.

Harvey V. Fineberg, M.D., Ph.D. President Institute of Medicine June 1, 2010 Page 4

I hope that you find the references of interest and that IOM will consider the points they raise in its future work.

Sincerely,

/s/ James P. Scanlan

James P. Scanlan

References:

- 1. Scanlan JP. Can we actually measure health disparities? *Chance* 2006:19(2):47-51: http://www.jpscanlan.com/images/Can We Actually Measure Health Disparities.pdf
- 2. Scanlan JP. Race and mortality. *Society* 2000;37(2):19-35 (reprinted in *Current* 2000 (Feb)): http://www.jpscanlan.com/images/Race_and_Mortality.pdf
- 3. Scanlan JP. Measuring health disparities. *J Public Health Manag Pract* 2006;12(3):293-296 (responding to Keppel KG, Pearcy JN. Measuring relative disparities in terms of adverse events. *J Public Health Manag Pract* 2005;11(6):479–483: http://www.nursingcenter.com/library/JournalArticle.asp?Article_ID=641470
- 4. Scanlan JP. Can We Actually Measure Health Disparities?, presented at the 7th International Conference on Health Policy Statistics, Philadelphia, PA, Jan. 17-18, 2008: Abstract:

http://www.amstat.org/meetings/ichps/2008/index.cfm?fuseaction=AbstractDetails&AbstractID=300283

PowerPoint Presentation: http://www.jpscanlan.com/images/2008_ICHPS.ppt Oral Presentation: http://www.jpscanlan.com/images/2008_ICHPS_Oral.pdf

5. Scanlan JP. Measurement Problems in the National Healthcare Disparities Report, presented at American Public Health Association 135th Annual Meeting & Exposition, Washington, DC, Nov. 3-7, 2007:

Abstract: http://apha.confex.com/apha/135am/techprogram/paper_153201.htm
PowerPoint Presentation: http://www.jpscanlan.com/images/APHA_2007_Presentation.ppt
Oral Presentation: http://www.jpscanlan.com/images/APHA_ANNOTATED.pdf
Addendum (March 11, 2008): http://www.jpscanlan.com/images/Addendum.pdf

6. Scanlan JP. Study illustrates ways in which the direction of a change in disparity turns on the measure chosen. *Pediatrics* Mar. 27, 2008 (responding to Morita JY, Ramirez E, Trick WE. Effect of school-entry vaccination requirements on racial and ethnic disparities in Hepatitis B immunization coverage among public high school students. Pediatrics 2008;121:e547-e552): http://pediatrics.aappublications.org/cgi/eletters/121/3/e547