

Disability Decline:
What We Know; and What We'd Like to Know^a

NIA-NBER Workshop Summary
NIH Stone House
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Introduction and Executive Summary

A brainstorming workshop was held on November 30, 2001, engaging a team of leading scholars in a collaborative exploratory discussion of the characteristics, causes and consequences of disability decline in the United States. The goals of the workshop were (1) to identify research findings relating to disability trends that represent areas of agreement in the research community, (2) to identify areas of ambiguity or disagreement, and (3) to develop some targeted foci for future investigations. What do we know now about disability trends, and what would we like to learn from future research? The workshop lays the foundation for both follow-up research activities and one or more follow-up meetings to compile new research findings, and to develop and extend the collaborative exploration of issues relating to disability.

The main area of agreement at the workshop was that there has been a significant decline over time in the functional limitations of older people in the United States; and probably worldwide. This finding has been confirmed using multiple datasets, multiple measures of functional disability, and multiple research methodologies.

More ambiguity was expressed about the rate, acceleration, and specific character of disability decline. The many variations and potential biases in survey measures of disability have led to differences in the details of findings from different investigations. Some data sources measure chronic illness rates; some measure direct functional limitations (seeing, lifting, walking, climbing stairs); some measure dependence in activities of daily living, ADLs (eating, getting in and out of bed, dressing, bathing, using the toilet); some measure dependence in instrumental activities of daily living, IADLs (housework, laundry, preparing meals, shopping, managing money, using the telephone); etc. Also, different surveys have different population samples, and different ways of asking people about their functional limitations. And while all data sources point to improvements over time in some measure of functional ability of older persons, it is unraveling the differences and details that provide a focal point for future investigations.

Many factors are part of the more comprehensive story of disability decline. These include improvements in physical health, improvements in cognitive health, improved ability to diagnose chronic illness, innovations in preventive medicine, innovations in the treatment of disabling illnesses, pharmaceutical innovation, improved diagnosis and treatment of mental

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health disorders, improvements in health-related behaviors, decreases in hazardous exposures, decreasing reliance on nursing homes for long-term care, the emergence of a broad continuum of living arrangement options, improvements in the technology of assistive devices, expanded use of assistive devices, environmental supports, changes in reimbursement for home health care, expanded elder care and elder support programs, etc. Putting all of this together is complicated. It is complicated still further by the fact that different disabilities may have been affected in different ways over time by different causal factors. Not a lot has been done to put together and reconcile the many data sources—or the many components, causes and reasons that people are better able to function independently.

The research agenda proposed at the workshop encompasses activities to better reconcile different disability measures; to better incorporate changes in living arrangements, assistive devices, and environmental supports into the story of disability decline; to decompose the composition of disability decline across disabilities, and across population subgroups; and to better understand the pathways through which people develop functional limitations. A variety of research methodologies were proposed, including international comparisons, focused studies of the evolution of individual health over long periods, environmental studies, and database development projects.

A final component of the workshop dealt with the costs, benefits and consequences of disability decline. A great deal of agreement was expressed at the workshop about two points. First, there have been very substantial economic benefits of health improvements over time. These can be measured in terms of work and other productive engagement, decreased caregiving costs, and most importantly, the “value” to individuals of improved health and health care. Second, innovations and investments in health and medical care technology and pharmacology have had benefits far exceeding their cost. While there was extensive and enthusiastic agreement on these points, follow-up research was recommended to more fully quantify the social and economic value of health improvements, the value of specific past investments in health, and the likely value of future investments.

Detailed Report

I. Disability Measurement

While a decline in functional disability has been shown in multiple datasets, based on multiple measures of functional disability, and using multiple research methodologies, the specific details of each disability study vary from one to another. While not necessarily inconsistent, the differences across studies point to the complexity of the disability decline story; and the need to pay close attention to how disability is measured differently in different data sources.

For instance, some studies suggest that the rate of decline in functional limitations is accelerating over time. Others suggest that the major improvements are in IADL limitations and not in ADL limitations; or in “functional” ability as compared with underlying “physical” ability. Both sets of investigations are measuring something that leads to these particular conclusions. What is not always clear is what specifically is being measured, and how does it differ from what is being measured in other studies. This part of the meeting was devoted largely to identifying these complicating details, and exploring follow-up research ideas to better understand them.

Complications in Measurement. There are significant variations in what is measured in different data sources; and even in the same data sources over time. The general focus of the surveys, the aspects of health and functional ability that are explored in different surveys, the wording of questions (“do you have difficulty...?” versus “do you need help...?”, for example), the framing and context of survey interviews, the field procedures, the response rates, the sample characteristics, the weighting techniques applied, the item non-response, the role of proxies, the loss to follow-up all lead to biased—or at least different—measurements.

Some of the variation in what is measured is deliberate. For instance, there are reasons to measure separately: (1) chronic illness rates, (2) direct functional limitations (seeing, lifting, walking, climbing stairs); (3) dependence in activities of daily living, ADLs (eating, getting in and out of bed, dressing, bathing, using the toilet), (4) dependence in instrumental activities of daily living, IADLs (housework, laundry, preparing meals, shopping, managing money, using the telephone), (5) living in nursing homes, or assisted living arrangements, and (6) functional limitations that have their source primarily in physical health, or those relating primarily to cognitive health, or those with component of both physical and cognitive health. And while most data sources point to improvements over time in some measure of functional ability of older persons, underlying this consensus is a recognition that different data sources are measuring different things in different ways.

Getting into the details of the data reveals many more issues and concerns. Differences in the sample are an important illustration. Some data sources attempt to be population representative, some are limited to the population outside of nursing homes, some over-sample individuals in poor health, some focus on individuals only in nursing homes, etc. More research could be done to reconcile differences in findings that result from the nature of the sample. A particular concern is the confounding trends in living arrangements. A decreasing portion of the

older population is living in nursing homes long-term; the receipt of home health care services is growing rapidly; and there has emerged a whole new continuum of housing options referred to generally as assisted living.

How does this affect survey findings? One perspective is that those living in the community now include parts of the population that formerly resided in nursing homes. So even if there were no changes whatsoever in health or disability in the population as a whole, one would expect to measure an increase in poor health and disability in community-limited samples. Put differently, the decline in functional limitations actually measured in community samples may underestimate the “true” decline in functional limitations in the population overall. However, the emergence of assisted living as a major and rapidly growing housing option, and the extent to which those in assisted living arrangements may or may not be included in various samples confounds even this interpretation of the findings. So there is still significant ambiguity about the extent, pace, and acceleration of disability decline.

Another complicating issue is the role of health aids, and the difficulty in interpreting survey responses that may be based on functional abilities either with or without the aids. The increased performance and use of assistive devices and environmental adaptations—canes, walkers, eyeglasses, electric chairs, walk-in showers, support rails, handicapped access facilities—all increase the ability to be independent of those with the same underlying physical limitation. So one wants to differentiate between functional ability improvement measures that result from the use of aids or environment, and those that result from true improvements in underlying health. Survey questions are often ambiguous, or are designed in ways that do not address explicitly this distinction.

Related to this are changes in the social environment, and the support systems available to older persons. Transportation for elders, microwave meals, grocery delivery services, meals on wheels, direct deposit—are all examples of environmental changes that relate very closely to how people will respond to disability-related survey questions. This raises even broader issues of how people develop self-perceptions about their functional ability, and how self-perceptions may change over time in ways that have nothing to do with “true” functional abilities. For instance, better pharmaceutical control of depression in the population may lead to more optimistic self-perceptions and more positive survey responses that have little to do with how far a person can actually walk. Or, perhaps, perceptions are what really matter, and “disability” is more a frame of mind than an underlying physical or cognitive limitation. So there is ambiguity even in what questions should be asked.

Interpreting changes in chronic illness rates is yet another illustration of how complicated measurement can be. Increases in measured chronic illness rates could result from true increases in illness prevalence, or from increased diagnosis of illnesses that were previously undiagnosed, or from improved treatment and longer life with chronic illness so that more people are alive to report having had the illness, or from a reduced stigmatism about honestly revealing illness in a survey. Decreases in measured chronic illness rates could result from similar (reverse) effects or, on the other hand, from improved treatment of the symptoms of chronic illness, so that it is no longer a concern. What exactly does it mean on a survey when a person says that they do or do

not have a particular health condition? Changes in disease severity, and the role of better disease management and control complicate interpretation even further.

The complication of measurement and interpretation of disability-related data is also evidenced by the large amount of “noise” in the measures of disability from one year to the next. The sample sizes in surveys of disability are generally large enough to show statistically significant differences from one year to the next; yet the measures of disability bounce around as if “true” population disability improves one year, and deteriorates the next; a seemingly unlikely proposition. If the ups-and-downs are statistically significant in themselves, what exactly is being measured?

A potential solution to many of the questions and complications addressed here may be found in part in intensive studies such as the Framingham studies, where a great deal of focused individual attention is placed toward understanding the details of the health and functional ability changes of individuals over time. The limitation in this case is the narrowness of the sample to one small geographic area and a population that is not at all representative of the country (or the world).

Another important point made in the characterization of health trends relates to health disparities. While chronic illness and functional disability are declining on average, the disparities between subgroups of the population are at least as large, and perhaps larger, than these health improvements. Indeed the difference in healthy life expectancy between socioeconomic groups in the United States may be as high as 20 years. But again, there is ambiguity in understanding the magnitude and character of health disparities. Thus it is important for continuing research to focus not just on overall population trends, but also on the differences among population groups.

Putting all of this together, one is left on the one hand with a general consensus in the research community that something very important has happened in recent decades. On average, based on findings from a whole range of data sources, disability measures, and research methodologies—it has been demonstrated convincingly that the functional ability of older people has been improving. Beyond this consensus, however, are many questions about the details, and a rich agenda for future research. Some of the follow-up research recommendations made at the meeting are as follows:

Follow-Up Research Recommendations

1. *Reconciling Different Disability Measures.* What can be done to reconcile the findings and trends found in different surveys with different measures of (a) chronic illness rates, (b) functional limitations, (c) ADLs, (d) IADLs, (e) uses of support services in nursing homes, assistive living arrangements, and home health care, and (f) physical versus cognitive health.

2. *Survey development.* What survey questions might be added or revised (a) to increase comparability across surveys, and (b) to more carefully and narrowly specify what is being measured by each survey question?
3. *Living Arrangements.* How does one integrate and reconcile trends in living arrangements, nursing home residence, and the growth of assisted living arrangements with various measures of disability in the overall population?
4. *Environment and Assistive Devices.* Can we better apportion people's ability to live independently among "true" physical and cognitive ability, objectively measured; functional ability with assistive devices; and functional ability with assistive devices, environmental supports, and other social changes that facilitate independent living even without improvements in underlying health?
5. *Data Linkage.* The linking of survey data with administrative medical records could be an important supplementary source of information about individual health; with the additional advantage of being more fully comparable across surveys. It would provide a depth of information about health as it evolves day-to-day that could accompany the greater breadth generally available in survey data over more extended intervals between interviews.
6. *"Objective" Health Measures.* Could survey respondents be asked to actually do something (walk, climb stairs, write something, use the telephone, etc.) in order to provide a more objective measure of functional ability than that which is self-reported in survey questions? Similarly, can more "Framingham-like" studies be developed with more broadly representative populations?
7. *Composition of Functional Disabilities.* A point was made that some functional disabilities are declining faster than others, or at different rates for different subgroups of the population. More should be learned about not just overall disability rates and trends, but the decomposition of those trends across types of disabilities and across population subgroups.
8. *Health Disparities.* In addition to addressing questions about improvements in health and functional ability overall, the research agenda should address the extent and sources of health disparities across population subgroups.
9. *Environmental Impediments.* Environmental surveys should be conducted to better understand the environmental impediments that limit functional ability, and how they relate to changing ADA standards and environmental support technologies, and how these environmental factors have evolved over time.
10. *Serious Disability.* It was recommended that surveys be supplemented to provide greater representation and more detailed information on those individuals with the most severe functional disabilities.

II. Causes of Disability Decline – Past and Future

Many factors are noted as contributing to the decline in disability rates. There was general agreement in the workshop about what factors should be included on this list, but less about the relative contribution of each factor to past (or future) disability trends. More research was recommended to better quantify the relative importance of these various factors. Among the causes of disability decline are the following:

High Tech Medical Innovation. There have been many “high tech” medical advances that have improved health. For example, intensive treatment for heart disease, and joint replacements for hips and knees have increased dramatically; and are likely to have important effects on functional ability. Future medical innovations are also likely to be important.

Pharmaceutical Innovation. There has been a rapid development in pharmaceutical treatments, as well as the applications of existing medications to new uses (such as aspirin for stroke prevention). The increased use of anti-inflammatory drugs for arthritis treatment is an important illustration of past pharmaceutical innovation. Future pharmaceutical advances are also expected to be important.

Mental Health. There have been significant advances in both pharmacological and other treatment of mental illness; and there has been a sizable increase in the portion of the population that is receiving treatment for mental illness. Particular advances have been made in the treatment of depression, but many other psychiatric disorders are also being treated more effectively. While the effects of mental illness on disability are apparently not well documented, advances in mental health treatment are believed to be a potentially very important factor in disability decline. Also, given the continuing high rates of under-diagnosed and under-treated mental illness, this may present a particularly valuable opportunity for continued improvements in mental health—and any associated improvements in functional disability—in the future. The relationship between mental health and functional ability was identified as another high priority area for future research.

Health-Related Behavior Change. Smoking rates have declined from 40 to 25 percent. (It was suggested that this alone could have caused as much as a 1 percentage point decline in disability.) Improvements in diet and alcohol abuse may have also contributed to declining disability. On the other side, recent increases in obesity rates may be a causal factor in the opposite direction.

Assistive Devices and Environmental Supports. The environment for individuals with functional limitations has changed dramatically over time. Canes, walkers, walk-in showers, electric chairs, eyeglasses, microwave ovens, ramps, elevators, ADA-required modifications to public buildings, transportation services, grocery delivery services, meals on wheels—have all served to increase the ability of individuals to manage independently. This has no doubt led to changes in reported disability, particularly in disability measures that ask about dependence on others for assistance.

Education and SES. There is clear evidence that education and other measures of socioeconomic status are highly correlated with chronic illness and functional disability. Indeed those with more education have roughly half the disability rates of those with less education. So as the population becomes more educated, disability rates should fall proportionately. However, while the relationship is extremely strong, the mechanisms through which education influences health and functional ability is not at all clear. For instance, education is related to treatment decisions (eg. education is highly correlated with hip replacements, though not knee replacements), and many health behaviors (such as smoking)—but still much of the effect of education on disability is unexplained, and the causal mechanisms are uncertain. This is a high priority area for future research.

Disease and Hazardous Exposures. Many infectious and contagious diseases have been largely cured, and exposure to many hazardous substances has been contained. Rheumatic fever, typhoid fever, syphilis, and measles are examples of contained diseases; dust, asbestos, and other carcinogens are examples of hazardous exposures that have been better contained. Importantly, some health-related changes that occurred decades ago may still have effects in decreasing chronic illness and functional disability among older persons today—because of the lifetime implications of childhood exposures. It was suggested that even garbage collection and drinking water quality improvements might be causal factors in disability decline. Indeed a number of investigators have identified the very significant correlation between the health of older people and their health-related exposures fifty or more years earlier as children.

A general observation was made that disability often results from combinations of conditions that evolve together over the course of later life, and that it is important not just to study the isolated causes of disability (and disability decline) but also the pathways through which disability tends to develop over time. This, too, was identified as a high priority topic for future investigations.

Some very rough illustrative calculations were offered about how much of the decline in disability might be attributed to certain tangible causes. One such illustration noted the doubling (a three percentage point increase) in the number of people with joint replacements over the past decade. The rough calculation multiplies this 3 percentage point increase by the portion of those people with joint replacements who have no subsequent problems (two-thirds) and then by the portion of those with disabilities who report arthritis as the only disabling condition (one-third)—concluding that joint replacements alone could lead to a 0.7 percentage point decline in functional disability. While this was clearly a rough and undoubtedly imperfect calculation in its details, it provided a frame of reference for how very specific causes could have very significant implications for population disability rates.

Another suggested approach to this work is to determine for individuals why they have functional limitations. For those in nursing homes, cognitive conditions and heart disease are the leading reasons offered for their nursing home residence. For those with difficulty walking or shopping, arthritis is the most common reason offered. For those with difficulty using the telephone, the reason is most commonly poor hearing. These responses give clues to the sources of disability decline, as treatment for arthritis helps people to walk and shop, and increased use of hearing aids may help people to use the telephone.

Finally, in the realm of potential future interventions, there appears to be an important role for integrating functional ability more fully into mainstream medical practice. Many decisions that people can make with their doctors (such as hip replacement, or depression treatment, or health-related behaviors, or pharmacological therapies) will affect their functional ability into the future. While progress has been made in integrating preventive health, mental health, cognition and functional ability into primary practice settings—much more could be done.

Follow-Up Research Recommendations:

11. *Pathways to Disability.* It was recommended that the causes of disability decline might be better analyzed not just by focusing on individual causal factors, but by studying the pathways through which individual health evolves into functional disabilities. More intensive work on these pathways—perhaps through studies like the Framingham study—were recommended areas of research development. (The pathways leading into, and through, joint replacement, and how they relate to the evolution of functional ability, were one illustration offered.) These pathway evaluations should also encompass disabilities that are congenital or acquired early in life.
12. *The Role of Education.* While education is highly correlated with disability, the mechanisms are not well understood. What about education leads people to be healthier? Moreover, years of education (which is how education is generally measured) may be less important than the quality, or nature, our career opportunities associated with education. More research on these mechanisms was recommended.
13. *Assistive Devices and Environmental Supports.* More needs to be learned about the extent to which assistive devices and environmental supports are being used today, as compared with the past, and how they change both the basic functional ability of individuals, and their ability to cope independently with functional disabilities. Again, a “pathways” approach, following individuals as they develop disabilities and begin using assistive devices, was a highly recommended approach.
14. *Mental Health.* More should be learned about how mental health relates to functional disability; and particularly how it interacts with physiological health, and with other causal factors, such as health-related behaviors.
15. *Hazardous Job Exposures.* It was recommended that more research be conducted on job-related exposures that lead over long periods to chronic illnesses and disabilities; and how changing OSHA standards and changing work environments may have contributed to health and disability trends.
16. *Condition-Specific Analyses.* It was recommended that research be conducted on the development and course of specific health conditions or behaviors, and their relationship

to functional ability. Studies might be conducted on arthritis, cancer, strokes, heart disease, smoking, or diabetes.

17. *International Comparative Analyses.* More research was recommended to identify and compare trends in chronic illness and functional disability across countries, and across population groups within countries. Cross-country variation may also help to more fully identify the causes of disability decline, and how various causes influence differently the disability trends in different countries.

III. Costs, Benefits and Other Consequences of Disability Decline

There are likely to be a wide range of potential economic benefits of disability decline. Some are easily measured, and some are more intangible. Two points of agreement were highlighted at the workshop—the first on the very substantial total economic benefits of health improvements—and second on the extreme cost effectiveness of medical research and medical advances in promoting health improvements that have a value far exceeding their cost. Among the benefits of health improvements (and the medical research that leads to health improvements) are the following:

Work and Other Productive Engagement. Since people are physically capable of working longer, more may choose to defer retirement and to continue working until older ages. This has implications for tax revenues, Social Security and other benefit programs, and for the overall productive capacity of the economy. And even if declining disability does not extend the period of paid employment, it is likely to affect unpaid work, such as informal caregiving within families; and volunteerism; and how people use their leisure time. No clear consensus exists on exactly how disability decline has (or will) affect work and time use, and it is an area where further inquiry is recommended.

Caregiving. Declining rates of chronic disability will also moderate the burden of caregiving, including informal care provided within families, care provided through home health care services, and care provided in long-term care institutions. This is a direct and measurable implication of declining disability.

Medical Spending. Disability decline may also affect medical care expenditures, though the relationships between medical costs and disability are more complicated. On the one hand, the investment in biomedical advances and the cost of providing state-of-the-art medical services may contribute importantly in enabling disability rates to decline. From this perspective, one might view the declines in chronic illness and disability as important products of *higher* health care spending. On the other hand, improvements in health and functional ability generally reduce the need for medical care, and may contribute to reduced costs. The combination of these factors complicates predictions of how trends in functional ability and trends in health care costs will relate in the future. This also raises the inter-related questions of when medical innovation leads to cost savings and, even when it does not lead to cost savings, whether the improved health associated with medical innovation is worth its cost.

It is clear that some health interventions—even very expensive health interventions—are cost-saving in the long-run. For instance, hip replacements for degenerative arthritis are quite expensive, but effectively keep people out of nursing homes, which are far more expensive. Similarly, many drugs are nearly costless to produce on the margin, and have enormous health benefits. Despite these selected illustrations, there is no clear consensus that medical innovations and reductions in disability will contain long-term medical costs. At one level, there is a hope that a healthier population will spend less on medical care over the course of their lives. But at the same time, new medical treatments that can improve or extend life, or more effectively treat conditions that are not fully treatable with current technologies, or treat conditions that become more prevalent in the future—may cost even more than those used today. The continued increase in health care costs would be a more likely extrapolation of historical experience, despite improving health and functional status.

An important point made at the workshop is that people value health very highly relative to other things, and despite their improving health, are likely to continue spending more on whatever cutting-edge health interventions may make a difference. And with continually increasing standards of living, it is likely that an ever increasing portion of economic resources will be devoted to health.

“Value” to Individuals of Improved Health. A more general question was whether health interventions and the associated improvements in health have been worth their cost in some broader sense. On this question, the consensus of the meeting was clear. By most measures, the value to individuals of past advances in health have far exceeded their cost. One measure of the value of the decrease in cardiovascular disease is \$30 trillion. And, on the margin, it is likely that future improvements in health, and advances in medical practices and medical treatments that enhance health will be worth far more to individuals—on the margin—than investments in any other component of the economy. Indeed some compare the relative benefit of devoting economic resources to health in the 21st Century to the relative benefit of economic resources directed to agricultural production in the 18th Century. It is the realm of the economy where we most value innovation for the future.

While there was general consensus on this point (that health is highly valued by people), the quantitative application of the concept raised some ethical questions of how one valued the lives of people in different circumstances. Does one value higher the life of someone with more economic means, because of their greater ability to pay? Does one value higher the lives of people in the United States than in less developed countries, or in countries where less is spent on medical care? And does one value differently individuals at different ages? What is the best way to measure the “social” value of health in some aggregate way?

Value to Others of Improved Health. In addition to the value to individuals of improvements to their own health, people certainly also value health improvements to others, such as family members and friends. This too might be counted toward the aggregated economic value of improved health.

Spillover Effects. Spending on health research and health care may have significant spillover and multiplier effects in the economy as a whole. Many service industries are fueled by

medical care and health-related services. In addition, there may be a multiplier effect to medical research (rather than diminishing returns) as the combination of medical advances reinforce each other and pass some significant threshold of health improvements that would be impossible to reach without a heavy multi-faceted investment.

At a broader policy level, a question was raised about whether the incentives of our health care system contain incentives for medical advances that enrich providers; rather than medical incentives that maximize population health. And whether our health care system moves us efficiently toward beneficial applications of new and cost-effective technologies as they become available? Specifically, do cost saving pressures limit or delay health expenditures that could have long-term net value in improving health?

Follow-Up Research Recommendations:

18. *Disability and Time Use.* More should be learned about how declining disability impacts work and retirement behavior, unpaid work such as caregiving within families, volunteerism, and time use more generally.
19. *Measurement of Social Value.* How should one measure (quantify) the value of health improvements and, using such a measure, what is the social value of recent improvements in functional ability? How should one evaluate and combine the economic and social benefits as measured by formal work, informal work, reduced benefit costs, reduced burden of caregiving, savings in medical expenditures, and the value of health and life to individuals and to others?
20. *Worthwhile Past Investments.* Using these measures, what private and/or social investments have been most beneficial in improving health?
21. *Worthwhile Future Investments.* What private and/or social investments are likely to have the most beneficial implications for the future? Also, given the likely value of future investments in health research and public health, what level of economic resources should we be devoting to health going forward?
22. *Quality of Life.* Finally, more should perhaps be done to differentiate between health investments that prolong life in an unhealthy state, and those that promote a high quality of life. Joint replacement is certainly an illustration of the latter. Some uses of chemotherapy may illustrate the former.

APPENDIX PARTICIPANT LIST

At-Large Participants

David Cutler, Organizer	Harvard University and NBER
Barney Cohen	National Academy of Sciences
Robert Fogel	University of Chicago
Vicki Freedman	Polisher Research Institute
Stephane Jacobzone	Org. for Economic Cooperation and Development (OECD)
Ellen Kramarow	National Center for Health Statistics
Ken Manton	Duke University
Michael Marmot	University College London
Bill Marton	Office of the Asst. Secretary for Planning and Evaluation (ASPE)
David Meltzer	University of Chicago and NBER
Robert Schoeni	University of Michigan
Teresa Seeman	University of California at Los Angeles
Sam Silverstein	Columbia University
Hugo Sonnenschein	University of Chicago
Timothy Waidmann	Urban Institute
Robert Wallace	University of Iowa
David Wise	Harvard University and NBER
Richard Woodbury	National Bureau of Economic Research

NIH Participants

Vicky Cahan	National Institute on Aging
Angie Chon-Lee	National Institute on Aging
Jennifer Harris	National Institute on Aging
Tammy Harris	National Institute on Aging
Richard Hodes	National Institute on Aging
Miriam Kely	National Institute on Aging
Raynard Kington	Office of Behavioral and Social Sciences Research, NIH
Kathy Koepke	National Institute on Aging
Georgeanne Patmios	Office of Behavioral and Social Sciences Research, NIH
Rachel Permuth	National Institute on Aging
Judy Salerno	National Institute on Aging
James Schuttinga	Office of the Director, NIH
Laura Shrestha	National Institute on Aging
Sid Stahl	National Institute on Aging
Jane Sure	National Institute on Aging
Richard Suzman	National Institute on Aging
Molly Wagster	National Institute on Aging