Artists Health Care Task Force:

A Report To Congress

Mayor's Office of Cultural Affairs
Artists Foundation
Boston Health Care for the Homeless

Boston, Massachusetts
July, 1994

Cover Credit: Boston visual artist Bart Uchida working collaboratively with Christopher Kirwan and Matthew Urbanski are creating an interactive learning environment for the Dorchester House Courtyard. Dorchester House is a multiservice center for the Dorchester community and is under the umbrella of Federated Dorchester Neighborhood Houses, Inc. (Services include pre-school activities, health care services, after-school projects and English as a second language.) Boston youth from low-income families are working collaboratively with the artists to physically create an environment in the courtyard that is a counterpoint to the urban landscape. The youth were recruited through the Summerworks Program, a youth employment and training program funded by the state under Title IIB of the Federal Job Partnership Act.
This project was funded by the City of Boston and the LEF Foundation.

(Photos by Toru Nakanishi.)

The Mayor's Office of Cultural Affairs, originally established in 1986 as the Office of Arts and Humanities, is a long-term planning and advocacy agency for the arts and humanities in Boston.

The Artists Foundation is non-profit arts organization established in 1973 to foster the development of artists in all disciplines and to advocate for artists on a public policy level by identifying problems experienced by working artists and engaging public and private agencies and artists in a common effort to discover solutions and lobby support.

Boston Health Care for the Homeless, established in 1985, has pioneered a model of service delivery in which multi-disciplinary teams of physicians, nurses and case managers have integrated non-traditional street and shelter clinics and outreach services with the traditional medical care offered in Boston's renowned teaching hospitals.

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OFFICE OF THE MAYOR
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Boston is one of the great cultural centers of the United States. Many of our arts organizations and museums are recognized world-wide as the best in their field.

Artists make a tremendous contribution to the vitality and liveability of our City. They live and work every day in the shadows of some of the finest hospitals in the entire world, and yet they cannot get affordable medical insurance - either because they have pre-existing illnesses or because health insurance premiums have risen far above any amount they can afford. Universal Health Care is the right medicine for Boston.

This report is a result of a series of meetings that were hosted by the Artist Health Care Task Force last Spring. Based on the testimony that was gathered from artists who attended, recommendations have been made that impact the issue of universal health care. The President and Mrs. Clinton have made this issue their top priority. We need to remind Congress that they were sent to work for the American people, and the American people support President Clinton in his fight for Universal Health Care.

Thomas M. Menino
Mayor of Boston

I. INTRODUCTION

The Mayor's Office of Cultural Affairs, the Artists Foundation and Boston Health Care for the Homeless joined forces in December 1993 to form an Artists Health Care Task Force to address the fact that Americans who work in the performing, visual and literary arts have not been seen in the national health care debate as a unique constituency with unique needs.

A 1991 national study by the American Council of the Arts has demonstrated that thirty percent of performing, literary and visual artists in large cities are without health insurance--almost twice the national average of all uninsured persons. In Boston, many uninsured artists are served by Boston City Hospital as well as other academic medical centers and neighborhood health centers in the city.

Artists have also been categorized as a high risk population by many insurance companies. Some insurance companies have effectively redlined or refused coverage to artists because of the perception of a high incidence of HIV and AIDS, fluctuation in incomes and/or low income and the occupational hazards associated with working with potentially toxic materials. Often times even the lowest priced health plans are out of reach for the majority of artists. Presently 43 percent of insured artists are at risk of losing their health insurance.

The Artists Health Care Task Force held a series a panel discussions in March and April of 1994 to gather public testimony and recommendations from artists of all disciplines on the issue of health care reform. The Task Force used Boston as a model to speak to the needs of the artists community. The findings will be used to help make health care in Boston, one of the top medical centers in the country with one of the highest concentrations of hospitals and medical facilities, accessible and affordable for the artists who work and live in the city.

Included in this report are the Artists Health Care Task Force's recommendations and the written testimonies submitted by artists to the task force. We are hopeful that this report will be a first step in documenting the magnitude of this issue and that it will offer recommendations that speak to the very real needs of artists who contribute so much to the quality of life in our country.

--Bruce Rossley
Commissioner
Mayor's Office of Cultural Affairs
City of Boston

A "Typical" Story

A young musician is surrounded by Harvard medical students in his 10th floor room at the Brigham and Women's Hospital in Boston. It is May and these second year students are no longer new to the wards. In roughly four months, they have learned the basics of history taking and physical examination--skills which embody both the art and science of medicine. The medical history--the story of the patient's symptoms, past illnesses, family and social history--provide the information that will be used to establish a working diagnoses and plan of medical care. In an era of advanced diagnostic technology, the skills that were taught by Sir William Osler over a hundred years ago remain the cornerstone of medical diagnosis.

Nick presented to the emergency department at the Brigham and Women's Hospital with a severe headache and a stiff neck. He had been in good health up until the previous day when he noted a nasal discharge and a mild headache. He had never been seriously ill in the past. He takes no medications. He does not use recreational drugs. His sister died of a cerebral hemorrhage at age 8.

"How did the patient appear on presentation?" The students' preceptor is trying to teach them a key diagnostic skill--how to recognize a critically ill patient, make a rapid assessment and intervention. According to the history taken in the ED, he was "Pale. Diaphoretic. Ill-appearing" The attending emergency physician and medical resident who saw him in the ED performed a lumbar puncture and administered antibiotics. The working diagnosis was bacterial meningitis. Nick had resisted going to the hospital earlier in the day even though his headache was becoming progressively more severe.

Nick supports himself through his own bicycle courier service. He has played the drums since he was 10 years old and has played professionally in a number of bands over the years. He hopes that one day his talent will take him to the top of his profession. Until that time, he is prepared to live modestly. He makes less than $1000 per month as a courier--enough to pay for food, a loft space, child support but not health insurance. He cannot afford bills from the hospital on his meager budget. Only upon the urging of a close friend did he finally agree to go to the emergency department. It is likely that had Nick delayed any longer, he might not have survived. As it is, he has lost part of his vision and will need to be in the hospital for weeks to come. It turns out that Nick has an extremely rare genetic disease called Osler-Weber-Rendu syndrome which has led to malformations ("AVM's") of his blood vessels. In his sister's case, these malformations in the blood vessels of her brain led to a fatal cerebral hemorrhage. In

Nick's case, malformations in the blood vessels in his lungs coupled with a minor infection led to meningitis and abscesses in his brain. It will take precisely the sort of expertise and technology available at this renowned teaching hospital to ensure that Nick will recover and suffer no further relapses.

Nick told the social worker who visited him in the hospital that he was plagued with thoughts of becoming homeless because of the huge debt he is incurring. It is possible that Nick may be eligible for free care--that his bill will be paid through the uncompensated care pool in Massachusetts. If he is not eligible for free care, he will be saddled with tens if not hundreds of thousands of dollars in medical bills. Furthermore, Nick has not only learned he has a rare genetic disease called Osler-Weber-Rendu syndrome. He may also soon discover he has another problem that may jeopardize his health--a "pre-existing condition". Even if he is able to afford it, Nick may not be able to obtain health insurance.

On the wards, the medical students have learned that the patient's social history is important in the formulation of a therapeutic plan. Their preceptor asks them to consider "psychosocial" factors in a plan of care for each of their patients. A woman in her sixties who has hypertension cannot afford the blood pressure pills that she is told she must take to avoid the risk of stroke and heart disease. "How will we ensure that the patient gets her medication?" A twenty-eight year old man has been in a car accident and has sustained minor bruises. His blood alcohol level at the time of the accident was .260. "How will we address his alcoholism?" A 45 year old man has been beaten up by a street gang and has sustained a tib-fib fracture. He will need a long leg cast but can be discharged from the ED. "Can he? How about if he's homeless?"

And finally, what will we advise our colleagues in the arts--who have perhaps trained as many years in their profession as we have studied medicine. Put aside your music, dance, theater, painting, poetry. Put aside everything which lightens our spirits, questions our assumptions and buoys our despair. Put aside all that you love--or risk your life. We have asked artists to live a life of poverty to follow their vision. Must they also give up their health?

--Robin Cuddy, M.D.
Chairman,
Board of Directors
Artists Foundation

"A Clinician's Tale"

My involvement in the health issues of artists has an unusual origin. In the summer of 1985, I had just finished a residency in internal medicine at Massachusetts General Hospital and took a job as a physician with the Boston Health Care for the Homeless Program. In addition to regular clinics at Boston City Hospital, I also spent three nights a week working in the Nurses' Clinic at Pine Street Inn in the South End of Boston. I was overwhelmed by the competency and commitment of the nurses. I learned to listen carefully to their advice as I tried to provide primary and preventive care for individuals who had only known long waits in crowded emergency rooms and impersonal care from complex bureaucracies. The clinic teemed with homeless persons suffering from a litany of common medical problems such as hypertension, diabetes, heart disease, communicable diseases, AIDS and cancer. While a condemnation of our society's ability to care for the our most vulnerable citizens, the clinic proved a provocative challenge for the skills I had acquired over the four years of medical school and three years of residency.

In the early fall of 1985, I began to notice a trickle of young and hesitant men who came to the clinic and seemed decidedly uncomfortable but determined to see me. As I learned only after caring for them for many months, they were young painters just out of the Museum of Fine Arts School and living in lofts on Paul Sullivan Way adjacent to the shelter. One had brittle diabetes; another suffered from asthma--neither had health insurance and they had come in sheer desperation to the free clinic. Certainly, both of these illnesses can be easily managed with the proper primary and preventive care, and the failure to do so often results in needless and costly hospitalizations. Both had been turned down from an inexpensive health plan because of "pre-existing" illness; neither could afford health insurance. Each knew the ultimate economic disaster associated with future hospitalizations. Their dilemma was, and remains, exasperating and foolish in a society of abundance. Comprehensive health insurance and access to primary care would clearly save society many health care dollars. Furthermore, universal health coverage does not only make economic sense; it is a moral imperative and a basic human right.

--James J. O'Connell, M.D.
Executive Director
Boston Health Care for the Homeless

II. THE ARTIST AND THE COMMUNITY

The President and the Administration are looking at holistic approaches to solving problems, and the arts are part of the solution to social problems. The young man who picks up a clarinet or a paintbrush is less likely to pick up a needle or a gun. He's got better things to do. He's hooked on art.

--Jane Alexander
Chairman, NEA
January, 1994

Even as the federal government wrestles with the creation of a new health care system, many Americans already pursue alternatives to traditional medicine, particularly those practices that emphasize the importance of the mind/body/spirit connection.

--Paul Master-Karnik, Ph.D.
Director, DeCordova Museum
Boston, Massachusetts
May, 1994

At this moment in history, citizens--artists included--ponder the outcome of this nation's attempt to reform the health care system. The impulse for health care reform resides in a moral tradition that is tied to the principles of justice and community. Since this nation's inauguration, artists have been a vital force in creating and communicating the vision of our common community. And when that community becomes fragmented--as it has been by the AIDS epidemic, homelessness, substance abuse and violence--artists find ways to build bridges, nurture imaginations and bind communities.

In Boston and throughout the nation, artists are collaborating with community organizations, in the words of Jane Alexander, "to communicate, to heal, to offer hope." Octogenarian

Allan Rohan Crite who worked in Roosevelt's WPA project is a community based artist whose home, the Allan Rohan Crite Museum, located in the South End of Boston is a center for artists, youth and the residents of the city. Crite--whose work is in the collections of the Smithsonian, MOMA, the National Center of Afro-American Artists and the MFA in Boston--has mentored scores of artists and continues to inspire youth with his resiliency, courage and dedication.

World AIDS Day was established in 1988 by the World Health Organization to commemorate those who have been lost to the AIDS epidemic and to increase public awareness of AIDS. In Boston, on December 1, 1993, two arts organizations, the Artists Foundation and Mobius, the AIDS Action Committee, the Boston Phoenix, a local newspaper and WFNX, a local radio station collaborated in a day long event that featured work by visual, literary and performing artists. During the event, the AIDS Action Committee, the Massachusetts Department of Public Health and the Boston Department of Health and Hospitals manned information areas and distributed materials to the public designed to enhance understanding of HIV and AIDS.

Started in 1990 by the Cape Cod Women's Agenda, the Clothesline Project is a survivor created visual display of shirts made by women (or in memory of women) who have been victims of violence. The Artists Foundation, the Boston Rape Crisis Center, the Clothesline Project and a score of other community and arts organizations collaborated to host the largest Boston display of

the project to date. The day long event featured local writers, poets, victims of violence and members of the law enforcement community. Shirts were created and added to the clothesline in memory of victims of violence. The visual impact of the hundreds of shirts hanging together was both a tribute to the survivors and means to spark a dialogue in the community.

Award-winning photographer Donna Ferrato has spent the last 13 years taking pictures of women who have been subjected to violence and degradation by husbands and lovers. Although her work was initially ignored by the media, her photographs now appear in national news magazines (most recently on the cover of the July 4th issue of Time magazine). Along with other photographers, writers and visual and performing artists, she has focused a spotlight on an area that has been hidden in shadows for far too long.

The Barbara McInnis Arts Project is a collaboration between Boston Health Care for the Homeless and the Artists Foundation. Visual artist Bart Uchida and architect Chris Kirwan work with homeless guests in a medical respite unit with the mission of transforming the institutional setting of an old nursing home into "a healing environment." The patients have many ideas for projects in specifics areas of the building and have indicated that the projects should be, for the most part, both "beautiful and functional." The patients have also indicated that they want to work with the design team both in the design and construction phases of the project. It is anticipated that such a collaborative effort will enable guests to develop design and construction skills

and build self-esteem. In a current project, artists and homeless patients work together to transform a former "smoking room" into "a room of landscapes." And so, as bodies heal, perhaps there will also be some opportunity to stretch the imagination and nurture the spirit. Like World AIDS Day and the Clothesline Project, the Barbara McInnis Arts Project collaborations were funded, in part, by the Massachusetts Cultural Council, the state funding agency for the arts in Massachusetts.

Boston based photographer Melissa Shook has given a voice to homeless women through her interviews and documentary photography. Shook presents portraits of women--through photography, text, catalogue and video--that captures their individuality, challenges perceptions about the stereotype of "homelessness", and appeals to our common sense of humanity. Shook joins a growing rank of artists whose work--to paraphrase Anton Chekhov--poses questions in such clear and compelling terms that answers are demanded.

On a national level, the NEA has taken a leadership role in creating and developing collaborations between community organizations and artists. The Writer's Corps, funded through a partnership between the National Endowment for the Arts and the National Service Corps, will place sixty young adult writers in communities to work directly with children and adults and teach them to read and then write about their experiences. In Washington, D.C., San Francisco and the Bronx, the Writers Corps will organize programs in neighborhood centers for 10 to 17 year olds who have been involved in the criminal justice system, foster care or are

runaways. Said Jane Alexander: "We are pleased that the Writers Corps will join the first landing team of AmeriCorps members in uplifting the lives and spirit of inner-city youth." (Trescott "Arts Agency . . ." E1.)

It is becoming increasingly apparent to leaders in government, the business community and academia that artists make significant contributions to the public welfare and the common good. Proposed new national standards for arts education have been drawn up by a government sponsored coalition of arts educators, business leaders and performing arts professionals. Secretary of Education Richard W. Riley has enthusiastically accepted the recommendations: "We seem to be . . . to the rest of the world . . . a nation consumed by a passion for expression, be it through film, theater, music or the elegance of dance. Arts in education elevates and gives structure to that passion for expression and connection." (Trescott "Proposal Would . . ." 1) As an example of the potential impact of that "passion for expression and connection", Riley cites the success rate of the Washington, D.C., Duke Ellington School for the Arts which has the highest attendance record of all District schools, graduates 99 percent of its students and sends 95 percent to college. (Trescott "Proposal Would . . ." 1) In Ms. Alexander's words, "As communities strive to renew themselves, the arts tender hope. They offer our children outlets--creative, positive outlets--for expressing themselves and discovering their unique talents and self-worth." (Trescott "Arts Agency . . ." E1)

--Robin Cuddy, M.D.

III. ARTISTS AND THE ECONOMY

Artists have often had to overcome preconceptions about the way they lead their lives from those who claim that they are merely looking for a handout from society.

--Ashley Ackerman
ArtPoint
Spring 94

The Artists Health Care Task Force formed in December, 1993 to address the fact that many Americans who work in the performing, visual and literary arts have not been seen in the national health care debate as a unique constituency with unique needs. The Task Force recognizes that artists are the back bone of our national culture and are also the creative force that fuels every aspect of the advertising world on which our society is so dependent. Without our creative artists and thinkers, our economy and society would grow stagnant.

Many of the artists who perform or exhibit at our cultural institutions do not have health insurance and/or have income levels that are well below national averages. This section attempts to quantify and examine why professional art makers, one of our national assets, are a profession that has fallen through the cracks into the ranks of the "underserved."

Ironically today's funders of the arts in both private and public sectors have shifted their focus to funding projects and/or organizations that directly help the underserved or "low income populations." They seem to have ignored the fact that artists are one of those underserved populations.

A. Perceptions/Realities of Artists

In the present day labor structure of the art world, living/contemporary artists of all disciplines--with the exception of the few who have become "stars"--cannot earn a living from their work as artists and must have supplementary jobs to supply their income. Contrary to popular beliefs, the majority of artists do not receive grants--public or private--and the bulk of artists do not get paid adequately, if at all, for their creative work. The majority of artists must finance their art work with the income earned from their supplementary job(s).

A 1987 NEA study entitled, Artists, found that there was 1,503,000 artists employed as "full-time" artists (an increase of 64,000 since 1986) and stated that "most artists cannot make a living practicing their art and must do other work to survive." It should be noted that a 1989 version of the report stressed that the 1987 figure grossly underestimates the number of part-time artists in the country (Jeffri 99). Dancemakers, a 1993 NEA Report concluded that most choreographers do not earn a living from their art: "Notwithstanding their high levels of experience--on average almost ten years--the surveyed choreographers spend twice as much time in non-dance jobs as they did in choreographic ones to supplement income. About 80 percent of the respondents had jobs in addition to their work as choreographers and 30 percent had more than one." (Netzer 17)

Often times, artists hold multiple part time jobs because there may not be any full time jobs available in their field or the

full-time jobs available (either in their field or outside of it) are not "flexible" enough for artists to pursue their art career. Some artists are part time faculty at a university or several universities because there are not enough tenured faculty positions available. Part-time faculty salary is much less than that of tenured professors and usually does not include benefits-- such as health insurance. Performing artists need to have flexible work schedules to be able to attend auditions and call-backs. Performing artists who tour with companies must have jobs that are seasonal or allow long leaves of absences. Many artists work for "temp" agencies. Furthermore, the majority of "flexible" and part-time jobs artists take to support themselves do not offer health insurance.

Artists pay out a significant amount of their income to produce their art work. A 1989 survey on artists in ten different locations in the United States by the Research Center for the Arts and Culture at Columbia University found that approximately 80 percent earned "some" income from their art. Only 40 percent earned enough revenue from their art to cover the cost of producing their art. Fifty-five percent of the artists in the study "earned $3000 or less from their art work in 1988." (Jeffri 100). The Dancemaker report by the NEA had very similar findings on choreographers: "On average, the respondent earned $6000 from choreography (including $1,600 in grants) but had professionals expenses of nearly $13,000, incurring an average loss of $7,000. This represents a 2 to 1 ratio of expenses to choreographic

income." (Netzer 16) Visual artists seldom get paid for showing their work in non-profit museums and galleries--if the artists do receive a stipend, it usually does not cover the full cost of producing the art and the time the artists must take off from their supplementary jobs to prepare and install the work. Commercial galleries take 50 to 60 percent commissions for the art work they sell, but usually do not reimburse the artists for the materials used to make and present the work. Nor do the commercial galleries offer the artists they represent any form of health care coverage. It should be stressed that performing artists also lose or forego wages for having to take days off from their supplementary job to audition, practice and perform.

Artists' income is not commensurate with their education. The findings from the NEA's Dancemakers report and the 1989 survey by the Research Center for the Arts and Culture at Columbia University are indeed "bleak" given that they document the very low economic status of artists compared to their education levels. (Netzer 9) Even though 77 percent of choreographers were college graduates and/or had advanced professional degrees, compared to 21 percent of the U.S. population over age 25, choreographers income levels are astonishingly low. (Netzer 15). "Choreographers income is 34 percent below the median for women professionals in 1989." (Approximately 73 percent of surveyed respondents were women.) According to Netzer, "over one-half of the respondents had less than $15,000 annually on which to live (after choreographic expenses); 29 percent had less than $10,000. Only 12 percent of the

respondents had annual net incomes of $30,000 or more." (Netzer 16) The Research Center for the Arts and Culture study found that 60 percent of the artists surveyed earned $20,000 or less in total individual gross income. Sixty-eight percent of the respondents in the Columbia study were highly educated with college degrees and/or graduate degrees. (Jeffri 101)

Similar findings on artists' economic status have also been reported in a 1986 study by the Boston Mayor's Office of the Arts and Humanities. More than half of the artists who work in all disciplines in the city earn between $10,000 and $17,000. Eighty percent of the city's 7,000 plus visual artists earn less than $22,000 each year. A 1994 survey of close to 100 artists by the Artists Health Care Task Force indicates similar findings. Fifty-four percent of the artists who responded earned $20,000 or less in total gross income in 1993; twenty-six percent earned $10,000 or less. Only 23 percent of the artists surveyed earned over $25,000. *None of the economic studies take into account or quantify how many artists do not have health insurance or how much they pay in out of pocket expenses for health care.*

B. Artists and Health Care

National Study

A national study conducted by the American Council for the Arts in 1991 of artists of all disciplines entitled, Study of Health Coverage and Health-Care Needs of Originating Artists in the United States, provides grim data on artists and health care. The American Council for the Arts study found that 30 percent of

artists living in big cities are without health coverage. This is twice the national average (15 percent of the general population are uninsured). Eighteen percent of all artists surveyed did not have insurance. Of those who could not afford health insurance, 55 percent are in the 36 to 45 age range. Thirty-four percent of the uninsured artists stated that they do not have access to a group health insurance plan. The study also revealed that an artist with more income derived from artistic endeavors is less likely to have health coverage, while 57 percent of the artists with insurance are covered by a plan obtained by an employer, the government or a parent. According to the study, 43 percent of insured artists are at risk of losing their health insurance as insurance carriers eliminate coverage through membership in associations such as artists' organizations or escalate prices for individual policies. When the premiums go up on such plans, many artists are priced out of the market.

C. Artists Health Care Task Force Findings

The findings from the March and April 1994 public hearings held by the Artists Health Care Task Force further clarify the problems artists had with the existing health care system. The task force found that:

- Artists, in general, forgo care. If artists do take advantage of medical care, they usually go when it has reached emergency or catastrophic conditions. Many artists fear not being able to pay for the medical care and/or fear being diagnosed with a pre-existing condition--thus possibly making them ineligible in the future for health insurance.

- Often times, low-income artists are not aware that they may be eligible for free care or care based on a sliding scale fee and a majority of those artists who are aware do not take advantage

of such services because they do not want to take services from what society has deemed the deserving poor--women, children and the elderly.

- Like many of the working poor, artists noted that they were unable to pay for prescriptions and/or refills due to their limited discretionary income.

- Many artists work part-time in order to have the time and flexibility they need to create their work. Often times, artists held multiple part-time jobs to make ends meet. The majority of these jobs do not offer health insurance.

- Artists noted that their income fluctuates year to year, even month to month and mentioned that sliding scale fees or free care based on pay check stubs can be problematic. Their income fluctuation also proves frustrating when trying to pay medical bills--since budgeting for the future or meeting payment schedules cannot be based on a fixed paycheck.

- Artists noted that they do not earn enough gross income to deduct "out of pocket" medical costs from their taxes.

- Performing artists--particularly dancers--noted that they often needed to seek alternative medicine such as acupuncture and chiropractic which is not covered under may insurance plans.

- Some artists stated that they do not qualify for health insurance because of pre-existing conditions and many said that they were "locked into" the jobs they have in order to retain health insurance benefits and/or because they had a pre-existing condition.

- Some artists stated that they are employed by small non-profit organizations that operate on a "shoe-string" and these organizations are not large enough to have a group plan and/or cannot afford to pay for health care benefits.

- Almost all the artists stated that they would be willing to pay for health insurance and health care but they have found health insurance to be economically out of reach.

- Artists stressed that they need a plan that is unrelated to work status and is affordable to those who have limited discretionary income.

D. Conclusions:

Even though artists are the creative energy supporting the culture industry, they are poorly paid and must supply their

incomes by supplementary jobs. Often times, these jobs do not provide health care coverage. In essence, there is a dual labor market structure in the art world that profits from poorly paid artists. The "high wage" sector of the art world is dominated by non-artists, while the "low-wage" sector is reserved for artists. The cultural industry of the United States is dependant on the poorly paid artists, "In fact the largest subsidy to the cultural life of this country does not come from corporate donors, the government, or from patrons but from artists--through their unpaid or underpaid labor." (Woodcock 126) Artists are the working poor of the art world and like most "underserved" populations, their needs--including the basic need of affordable health care--have been ignored.

--Kathleen Bitetti
Artist and
Executive Director
Artists Foundation

IV. RECOMMENDATIONS

The Artists Health Care Task Force recommends that Congress consider the merits of a single payer system that would enroll all citizens. It would seem that many features of an employer based system could be problematic for artists as well as other citizens such as the working poor, the unemployed, the self-employed, and persons with multiple part-time jobs. A single payer system would also be more likely than an employer based system to:

- **eliminate administrative inefficiency;**
- **scrutinize the quality of care delivered;**
- **contain health care expenditures by focusing on areas where there is waste and inefficiency in the health care system;**
- **cover citizens who are self-employed, unemployed or employed in multiple part-time jobs;**
- **provide health care as a basic human right for all our citizens.**

Ultimately, whether the nation adopts an employer based system or single payer system, the needs of artists who contribute so much to society must be addressed. Jane Alexander, the first performing artist to chair the NEA in its twenty-five year history, acknowledged at the 1994 Show Biz Expo that "health care for artists is in dire straits--the minimum earnings level required for coverage under Actor's Equity has risen dramatically, and with the devastating impact of AIDS, many artists have no health care available. My hope is that this travesty is remedied by the

National Health Care Plan the President is pursuing." (Alexander 4)

The development of a system of health care that ensures this basic human right and contains health care expenditures is a moral and economic imperative for this nation. Any system will need to consider the fact that the working poor do not necessarily have the discretionary income to purchase even a low-priced health insurance plan. Furthermore such plans may not pay for out of pocket expenses such as prescription medications. To quote Rashi Fein of the Department of Social Medicine at Harvard Medical School: "It has become obvious that employer based private insurance operating within a system dominated by experience rating cannot reach everyone." (Fein 49)

The unemployed, the self-employed, those whose employers do not provide insurance and those with pre-existing conditions are left out of the loop. A single universal system in which all citizens are enrolled in a single program--such as the Medicare model--would "sever the link to employment." (Fein 50) With an employment based system, there would need to be mechanisms to cover persons who have one or multiple part-time jobs as well as "separate mechanisms to provide continuity of coverage for individuals who change employers or location. They would have to account for differing ability of employers to finance insurance and provide approporiate subsidies for 'marginal firms' as well as for start up enterprises." (Fein 50)

Each of these mechanisms adds to the bureaucratic complexity

and administrative costs of the plan and does nothing to improve the health of the individual or the nation. Furthermore, as Rashi Fein notes, a single enrollment program:

> "means a single payer or, more appropriately, a single purchaser of services. This situation leads to the standardization of forms, to electronic billing and to various measures that reduce confusion, delay and the costs of administration in today's system. The purchaser would not only pay the bill for services but also accept a broader responsibility to focus on issues of quality of care, unnecessary services and value for money. Each of these activities contributes to cost control." (Fein 50)

Artists tell us truths about ourselves as individuals and as a community that move us, anger us, and sustain us. There are some who say that this country has not valued the arts or the artist. It was recently reported in the New York Times that the entire budget of $170.2 million dollars for the NEA is smaller than the Defense Department's budget to support military bands of $189.1 million. (Goldberger C13) The issue of government funding for the arts is one which has stirred much debate in recent years and reasonable people will find cause to disagree. But does not justice require that this nation ensure health care to all its citizens--artists included?

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V. ARTISTS' TESTIMONY

STAGESOURCE

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ODUCERS

March 28, 1994

I have worked as an arts administrator since 1966 and have had health insurance since 1980. As an arts administrator, even though I am an employee (unlike most artists) I work for organizations too small to have group health plans so that all I can get is non-group insurance. You pay more for less in nongroup, because you have no bargaining power. Like other people with a chronic disease, including, of course, AIDS patients, I cannot ever change from the health insurer I had when the disease was diagnosed because no other insurer will cover a pre-existing condition. I was, however, very lucky that I was insured already when I was diagnosed with diabetes.

I am fortunate also that my employer pays for half of my health insurance premium, which is impossible for most small arts nonprofits. Even with this help I spent over $7,000 from my own pocket in 1993 for premiums and unreimbursed medical expenses. My insurance, for example, pays for my insulin but not for the syringes with which to inject it, nor for lancets and test strips with which to test blood glucose levels, on the ground that these are "not medically necessary."

Next to availability, simplicity is of the greatest importance in health care coverage. The paperwork now necessary is baffling, time-consuming and fraught with uncertainty, and it is increased by the internal policy (acknowledged to me by an employee of Blue Cross/Blue Shield) that they reject almost everything for specious reasons and hope that much of it doesn't come back to them. Virtually every claim that I submit is first rejected but after I contest the decision, the claims are paid.

About 7 years ago I was working for the Massachusetts Cultural Alliance when they were trying to negotiate a policy to cover not only their employees but also their artist members. The insurer with whom they were negotiating told the Business Manager that they did not want to insure the Mass Cultural Alliance because they expected a high incidence of AIDS. The insurer would not put this statement in writing. The code now is "We don't want to insure your industry". A long-held prejudice that artists are high risk has escalated with the advent of AIDS.

Alternative medicine is often important to artists and, in some cases (like mine--acupuncture relieves the pain of diabetic peripheral neuropathy and nothing else can) is the only efficacious course. It is, however, rarely if ever covered.

A few years ago, when I was on a trip to a country which shall be nameless but which has a much better health care system than ours, my son was bitten by a dog. When he had been stitched up in the nearest emergency room, I attempted to pay for the care. After several fruitless phone calls the staff told me that the system wasn't set up for payment from individuals and I should not worry about it. If we could see that day here I would gladly pay more taxes. They could hardly amount to an additional $7,000 a year.

Christine K. Connaire

88 Tremont Street Suite 714 Boston MA 02108 Tel. (617) 720-6066 Fax (617) 720-4275

Statement on Health Insurance for Artists

by Vera Gold

Eighteen months ago I left my place of employment, The Wang Center for the Performing Arts, where I was Director of Marketing and Director of Education/Outreach. While working at The Wang Center I had a family health insurance plan that was fairly extensive, with a $100.00 deductible per family member. I left my job to work more in the creative side of the arts and formed and organization, 96 Inc, a literary resource, and an artists collaborative, which has a very strong educational component. The Cobra plan that we were entitled to, cost $750.00 per month for the family of three (we paid $10,000 in 1993). The Cobra plan expired at the end of February, but the cost was becoming prohibitive and we could not continue in any case.

We have researched other health insurance plans and find that even catasthrophic coverage is very expensive. Our income is erratic and this past year we cashed in most of our savings to give 96 Inc a start. The insurance plans we have been offered are are over priced and do not cover preexisting conditions. My husband, a writer, has arthritis and is in need of medication. During the years we were covered by a family plan our cost for medication was $5.00 per prescription, but the Insurance Company controlled that plan, and sometimes did not allow a refill when it was ordered. The cost for many prescriptions range in price from $110 to $170. All three family members have problems with visionand need eye glasses and this is an additional medical expense.

I sincerely hope that health insurance will become available to artists.

Susan L. Nacco

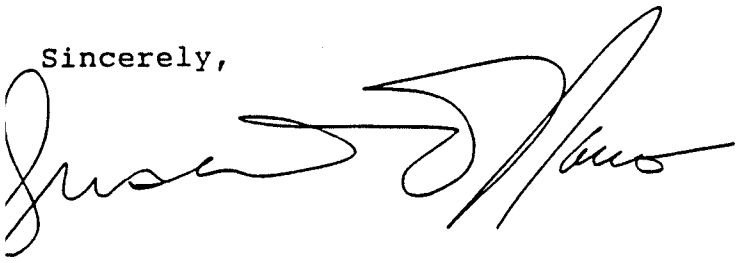
I have been an artist since 1984. I studied art in school, and have both BFA and MFA degrees. I know that art is what I want to do, and an artist is what I am. While in undergraduate school I claimed to have insurance so I would not have to pay to be on the school policy, which was inexpensive for insurance, but still too much for me to afford. In graduate school I subscribed to the school insurance, even though the coverage was very bad. Since graduation, I have not been able to afford health insurance. I was a waiter in a restaurant that offered a plan that would cost me $200. per month. This was out of my price range. Since leaving that position I have been working full time at a place that offers no coverage. I have researched into different plans through various organizations: Blue Cross and Blue Shield, National Organization for Women, and the American Crafts Council. None of these plans are affordable to me.

I have a number of friends in the arts. Some work full time at positions they hate because the job offers benefits. I have witnessed a friend claim to be someone else that had insurance to be able to receive emergency medical treatment because they could not afford it otherwise. I myself have cataracts that need surgery, but there is no way I can do that without affordable insurance.

I am an artist. I put a lot of time and energy into my work. That is what it is, work. In addition, I work for money to support myself. The jobs I work are not very high paying and they rarely offer benefits. Because I decided to pursue an art degree my job options are limited. I understand this fully, and I understood it when I made the decision to go to art school. But I do feel that I deserve the right to have affordable insurance. Medical rates are based on having insurance coverage, and at this point it is not even possible for me to be able to pay for a hospital.

Thank you for listening to my testimony.

Sincerely,



ARTISTS HEALTH CARE FORUM

Many of us feel we are physically infallible. Invincible. My husband Jeff did.)ne day back in 1984 (Dec. 17), I coerced him into a long, overdue general physical .t a cardiologist's office. He didn't want to go. "I'm fine." "Good", I said."I'll take you o lunch afterwards." Instead I ended up taking him to the emergency room at Beth srael. We spent that Christmas and New Years at the hospital where Jeff was diag- iosed with idiopathic cardiomyopathy(an enlarged heart), cause -- unknown. This vas a 32-year old man who lived moderately -- no substance abuse, didn't smoke, ode a bike everywhere. After two weeks he was released to dwell in our studios at)edrest with a visiting nurse coming twice a week to draw blood. Daily cocktails of nedications became his regimen. Previous to his onset we had joined BCBS non- group and now were in the midst of their interim period. We had to fight them to :over his costs.This was the beginning of our living on the edge medically. Jeff did vell. he wanted to keep painting so he took his medicine, took care of himself. The loctor said "Get on with your lives, yes, have your family." However,the door re- volved the day I left the hospital with our second child. Jeff was in severe heart fail- ure. Recommendation--HEART TRANSPLANT. An ideal candidate, he was accepted nto the program at Brigham & Women's. Too ill to live at the studio under my care, ie resided in the hospital the majority of the time. Jeff waited for a heart. His bed)ecame a miniature studio. On December 27, 1987 he became Heart Recipient #50. -le finished a drawing in case it grimly was his last before they wheeled him off. The transplant surgery took place adjacent to where they were delivering babies. We were surrounded by the arrival of new life, Jeff's included.

The dark clouds have not disappeared though. Every 3 months we now fall)ehind in our rent because it's better to pay the health insurance because when you lose this it's all over due to pre-existing condition clauses on health insurance policies. With Jeff's monthly medication & clinic visit costs of $1200.00, paying BCBS $556.00 a month is a deal,a plus covering any needs of the rest of our family)f 5. But is it really better to face eviction, compounded with the stress of ordinary survival as well as the stress of artistic survival? Many visual artists tend to live in substandard conditions because of trying to maintain both home and studio in one place or struggling to pay two rents. And what about if you have decided to raise a family like other parts of society! Most artists are classified self-employed working part-time at an extra job or they free-lance. They are generally not eligible for group policies and must either pay higher fees or go without insurance. OR wait until they are sick and end up hospitalized and absorbed into free-care systems and public assistance. Lower these costs. Allow artists to make their art. I don't object to paying for insurance. I object to being harnessed to a system thats too expen- sive. Jeff asks himself almost daily, "Was I resurrected, given this second chance at life so I could beat my brains against the wall to pay extraordinarily high rates of health insurance so I can keep on living? Or was it so I can keep making art and see my children grow?" In our case it is pay high or die. Let's get this right.

Do you have health insurance? **yes, Non-group for family.**
How do you pay for your hospital bills & prescriptions? **Insurance pays for 80%; we are responsible for the balance which we cannot afford so we apply for free care when applicable and remain in considerable debt.**
Do you have coverage for a chronic illness? **yes, 80%.**

Deborah K. Hull

F DE CASTRO 516 E. 2nd St. #303
SOUTH BOSTON, MA
02127

: Healthcare for Artists,

ear Representative,

The current states of my healthcare is abysmal. The payments of $100 a month, when one is self employed is a major cut when one considers the other insurance I must carry in order to survive as a business.

The prospects of improving my health care as I grow past 40 (the rates just went up) does not look good at all. Plus, my health is endangered by my occupation and only covers 75% and has a $1000 deductible. When the quarterly payment comes — everything else falls apart. The only real insurance I have is to be careful and stay healthy.

Sincerely, Jeff de Castro

"Artists to Discuss Health Care"

Testimony by Liz Hardy-Jackson
10 Mountfair Terrace, Hyde Park, MA 02136 361-4456
March 30, 1994

I would like to take a moment to congratulate the City's Office of the Arts and Humanities, the Artist's Foundation and Boston Health Care for the Homeless for holding this hearing. You have brought together a community that has limited access to health care. By doing so you demonstrate the need to discuss our health care and to be a participant in health care reform .

My name is Liz Hardy-Jackson. I live in Hyde Park, Massachusetts. I am a visual artist. I have several hidden disabilities. I need 5 medications daily. With insurance my prescriptions cost $15.00 per month, without the cost is about $250.00. I have health insurance because of a pilot program from the Dukakis administration that **allowed** people with pre-existing conditions to have insurance. This program was for small businesses and individuals. It was discontinued by the Weld administration. I was able to stay with my health care provider as long as I could pay the premiums. Currently, I have a job at a small non-profit organization. This organization picked up my health insurance and pays $223.73 per month for the premium. By the way, this premium has gone up 8% annually.

If I were to apply for a new job and the new company didn't have the same health care provider I currently use I would not dare take the job because I **will loose my insurance.** I cannot change insurance plans because of my pre-existing conditions therefore I don't change jobs. I t would be the same scenario to relocate.

We must have health care that is affordable, with no pre-existing clauses and with true portability from changing locations and changing jobs. Thank you very much.

March 28, 1994

I am a 26 year old female working artist in Boston. I have a B.F.A. from Tufts and The School of the Museum of Fine Arts. I have been supporting myself for the past eight years. I have two part time jobs as there is not enough work at a decent wage (or any wage for that matter) in the arts. One of my part time jobs offered health insurace to be paid for out of my paycheck but I was rejected based on a "pre-existing condition" which is occasional back problems (who doesn't?). Also, at this point I can choose to eat or pay for a health plan.

I have been relying on free care at the Brigham and Womens Hospital which is only good in case of emergencies in relation to gynecology (I have a tendancy towards irregular pre-cancerous cells found in my pap smear, a very common condition that must be monitored). I am not eligible for regular visits, however, since my last test came back normal.

By accident a bill came to my studio for $500.00 for a 20 minute appointment in which a colposcopy (microscope) and biopsy were the only procedures. This is a very common procedure which really only takes minutes to complete. I was seen only by a doctor and a nurse. What lab fees could cost so much? How much are the staff, doctors, and administration making?

I've heard people talk about where the money will come from to pay for health care reform (cigarette tax, etc.). Could a part of the solution be to cut the cost of health care? What exactly are the expences? What procedures are necessary? What is the profit and who is making it? I believe an investigation is necessary before an overhaul of the whole system can be realised.

A quick note on why the labor force and consequently the health care system is so distressed: The "recession" in some cases is an excuse to get more work for less pay and benefits out of less people (i.e. less expence). Employers (who often cry poor mouth while retaining the large salaries they had during the 80's boom) are not the ones taking paycuts and are often making as much if not more money percentage wise than before the recession. They use the fear of losing one's job not to mention health care as leverage to keep us satisfied with the least amount they can get away with.

Thank you very much for this honest effort to improve the quality of life for all Americans.

Sincerely,

Tema Levine

Tema Levine
516 East Second St.
South Boston, MA 02127
(617) 464-1041

VIEW OF RENA BASKIN (Actor, Singer, Narrator, an AFTRA Board member, and on HealthCare Committee for S.A.G.) WITH EXAMPLES;

Union actors can get health coverage from an union group if they earn a certain amount of money, but that eligibility earnings level is raised each year because health care costs are rising so fast the union can't afford to cover as many as before. Therefore, a smaller and smaller percentage of the membership is covered each year. Any medical insurance that is job related has a built in problem for the insured: If you are sick and can't work, or lose your job, you earn less and may not qualify the next year; AND even if you do, you have less with which to pay for premiums, co-payments, deductables, and non-covered necessary services. In other words, when you are out of work, or ill, and can least afford it , your expenses go up. In SAG, at the $7,500/year level you qualify for very basic insurance...no family, dental, mental health, chiropractic or other forms of holistic or preventive care are covered. AT the $12,000/year level you get more coverage, but there are still out-of-pocket expenses. Only a tiny percentage of artists of any type earn more than a simple living wage at their work. Most of us work several jobs just to make ends meet and hope we'll make eligibility year by year. It's stressful way to live, and stress often leads to medical problems, as we all know.

The middle-men (the insurance companies), in their own interests, hire thousands of people to process claims, to decide who gets covered, and what gets covered. They spend our money, and raise our premiums, to find ways to keep us from being covered when we are ill! It make no sense. It is the main reason our insurance costs ar rising.

Artists, particularly free-lancers, need a national plan that is unrelated to work status. Everyone in America should have health care when they need it, as a HUMAN RIGHT. We don't have life, liberty, or the ability to pursue happiness if we are dying, or ill and can't work. Under current insurance-company system, we are not free to pursue happiness. We are often forced to take and stay in jobs we merely like just to get medical insurance for ourselves and our families. We are not contributing our creative talents as fully as we might as a result, and we are not really free to choose our work if we must choose based on health security. A single payer system

would simplify, equalify, and reduce costs across the boards, and if everyone could afford to have check ups and preventive care, we'd all be healthier, need care less often and it would cost less to get well when we get sick, and we'd feel freer to work at whatever we enjoy and are good at... and when you enjoy your work, you feel better about yourself and contribute more to your society. When the majority of people (in the arts, especially) have to work at jobs (often more than one) just so they can get health insurance, or pay off medical bills, this is not the land of opportunity (for artists).

Examples: Veronica Lewis was a member of NETWA, an organization of theatre workers Boston actors that tried to start to get some clout to get what we needed for theatre folk who were non-union. This was before Stage Source existed. Veronica, an adult, living on her own, became ill (I don't know what the problem was), had no health insurance, and did not want to stress her parents finacially or burden or worry her family about her illness. So she didn't get help. I hadn't seen her in many years and hadn't known she was ill. It was a shock to me to learn that she had died because she had not had access to free or affordable health care. The general feeling in the community was that, had she had access to affordable care she would have chosen that route and gotten the help she needed to survive.

Audio-engineer: A friend of mine said that I could tell his story. He had an old injury form an auto incidient.. a disc problem.. which hadn't bothered him in years. While helping a friend move he pulled his back out and was in excructiating pain. When asked if I should take him to the emergency room (It was Sunday, no doctors availabe elsewhere that we knew of) he said "Absolutely not! I can't afford it. I have no health insurance. Suppose they say I have to stay for observation? Or that I require surgery? I have to try less expensive means first." Luckily he could afford to see a chiropractor and get some help, but his point should be noted for our new health care system plan. Currently insurance compaines will cover the big, expensive stuff in doctor and hospital setting, but not the less expensive, preventive or less invasive and less painful and dibilitating alternatives.. some of which could cure the patient and spare him or her the pain, inconviently long and usually (for freelancer) <u>unpaid</u> recovery period and huge expenses of surgery.

I feel we need a single payer health plan, equal across the board, for all American whether they work or not. Employers could offer extra coverage as employee incentives (i.e. private hosptial rooms). Overall, a small tax would be well worth paying for the peace of mind for freelancers and I believe, everyone would enjoy. It would cost less than this insurance company mess we have now. Insurance companies could focus on auto, home and other kinds of insurance sales instead. Maybe those of us who would be freed up from medical insurance costs could then afford home-owners insurance. Freelance actors, and artists of all kinds, need to be figured into the picture when the new plan is decided upon. Work-based insurance doesn't work for us.

I am one of those who has a side job so I can get health insurance. I have to pay for it but at least I'm in a group. I keep this job just in case I don't make the eligibility requirement for my "free" union coverage- lots of jobs + lots of stress!

-Rena Baskin

The early eighties was a very good time here Boston. We were in the midst of the Massachusetts ic. Consequently, for the acting community here e was lots of work for everybody. Television ductions, Films, Instructional Video, commercials ce overs, theatrical productions helped to support ibrant thriving artistic community. At the same e time all the work was available there was ery reasonable minimum necessary for full ticipation in any or all of the four I4's unions lth plans.

In the spring of 1984 I was diagnosed with angina was put on medication to help maintain my health. ver there was not the kind of illness that medication e would help. For as my workload increased, health had begun a slow steady spiral downwards a battery running out of juice. Minimal physical ition became painful and exhausting. Until ally on July of 1988 I had a mild coronary action

Rushed to a hospital in the early morning hours July 27th, I knew I did not have to worry about medical bills that would surely ensue from all , because I was covered fully by three seperate lth plans, from Screen Actors Guild (SAG) American ration of Television and Radio Artists (AFTRA) and ia Equity Association (AEA.

My progress while in the Newton Wellesley Hospital s not what was expected from my doctors so after days I was transferred to the Massachusetts General

Hospital here in Boston. After another week of testing and determined that I had 70% and 60% blockages in all the major arteries around my heart and that the only avenue left open to me, if I wanted a full life expectancy, was major surgery.

On Sept 1 1988 I underwent quintuple by-pass surgery (CABG (Coronary Artery By-pass Graft.) in which they use arterial grafts taken from my right leg and LIMA (Left Internal Mammary Artery) Due to some minor complications, such as a partially collapsed left lung, I was finally released on Sept 16, 1988.

Since that time my health has been, to say the least, remarkable. I have participated in two mini tri-athalons and when the roads are clear and the weather not too cold I average twenty miles a day on my bicycle.

Shortly after I had started my convalescence the bills started to arrive. For the surgery alone a 11 page computer print out detailing everything between the heart attack, the tests at Mass General, and then the surgery a bill of close to ninety thousand dollars. Because of my health insurance coverage my out of pocket expenses were less than three thousand dollars.

But a strange thing has happened to the world since then. First the Massachusetts Miracle is gone bust. So alot of work that used to be me as now just a distant memory

Add to that the (3) rising cost of health care
has forced the Unions all to raise their require-
ts for coverage. This alone has meant that only
3/4 quarter are able to make them summa-
ring lots of people who are once covered totally
ss!

As it stands now I am now only covered by
health plan offered by AEA which is basically
catastrophic insurance. If I were to try
ate health care given my history I would be
ated out of hand or given a plan totally beyond
means, which would in effect leave me
covered.

If I were to have the same circumstance
sen to me today I would be forced to live as
invalid on the government dole because it has
shown that usually only white men with extens-
erance get the kind of treatment that I need.

Health care should not be the province of the
h. It should be the fundamental right of
y person. For it has been said, and I live that
ry day of my life. If you have your health
have everything.

Sincerely

Jay Ginsberg

JAY ALAN GINSBERG
139 ADAMS ST. 53
WALTHAM, MA 02154

e United States Improvisational Theatre League • 30 Bellevue Avenue • Cambridge, MA 02140 • 617/864-1344

Nadette Stasa
theatre producer
casting director

I am a theatre producer and freelance casting director. The producing work I do is in its beginning stages and therefore doesn't even pay for itself. In order to generate income I work as a casting director and because financial security there is limited, I also work with a catering company to make ends meet. I presently pay $186.19 a month for health and dental insurance. I am on a plan called COBRA, which is an extension of a plan provided by a former employer, MIT. Through the COBRA plan I'm covered by HCHP, an HMO I am quite happy with. The amount I pay monthly is rather exorbitant, but mostly I'm glad just to covered. I've heard about group plans and deductibles but all that seems more complicated than a straight monthly fee for 100% coverage. And I really love the convenience of an HMO. Under the COBRA/MIT plan prescriptions are only $5 and that really adds up against being an individual member where one has to pay full price. As artists we are mostly self employed freelancers. I would like to see a health plan specifically designed for artists. A group coverage for artists. I would also like to see some comprehensible coverage for mental health care and alternative health care. As creative people traditional medicine is not always our greatest priority. Right now because I can barely make individual health care payments it is hard for me to conceive of providing coverage for people in my theatre company. I can't even pay them salaries let alone insurance coverage. But as the company expands I would be very interested in finding out about reasonable insurance possibilities for my staff, at least. But as I said, that sounds like a luxury I can't afford.

I would point out that rank-and-file artists, those of us who work daily on some aspect of our art without conern about issues such as fame and fortune, are simply striving to make a living in the fields we are trained for. The work we love. We face the same dilemmas about health care as any person in America.

Artists must plan their careers as if they were small business persons offering a service. In a typical year I work for 7 or 8 employers, each of whom issues me a W-2, makes withholding deductions for taxes and Social Security, and makes pension and health premium payments directly to the appropriate union. While it is a substantial benefit to an actor to have health premiums paid 100% by the producer employer, it is a drawback to have to constanlty switch back to "self-pay" each time a show closes and the coverage runs out. These realities drive people out of this business.

Until a couple of year ago Equity members could expect to receive health coverage throughout their employment in a show and for two to five months afterwards, depending on the level of coverage the employer had contracted for. The actor could not contribute in order to insure the higher level of coverage, although coverage for dependents could be purchased by the actor. Equity's plan since the early 1960s- the first time American actors were guaranteed health coverage- has been an indemnity plan written in New York. It was a decent plan, as far as it went, and many people felt that they were lucky to receive "free" coverage throughout employment and for however many months afterwards. If you worked often enough, went from show to show, you would always be covered, as I have been for well over a decade (one draw back was that I could get better coverage from my wife's HMO and that dental care was not covered by the plans).

But claims on the plan have been substantial in recent years, and the increased amount of "small" professional theatre around the country has contributed to heavy burdens on the Plan. There has evidently been an unforeseen amount of "adverse selection", by which i mean enrollment in the play specifically in order to make a claim under it. Within the union there has been controversy over the handling of these matters, and indeed over the new procedures now in place--AIDS and the perception that performers are more at risk than others.

Begining a year ago coverage rules have changed. Now an actor is covered at one of two levels (again, based on the premiums paid) depending on whether or not he or she has worked 12 weeks or 20 weeks in the past year. The plan "looks back" at your record every three months. If you qualify, your coverage rolls forward. If not, it will terminate. Once qualified your record will not be reviewed until the year's coverage has expired. This system has helped "save" the health plan, but it has had a significant adverse effect on actors in regions such as New England and other areas away from the three major cities. It has had a substantial effect there as well. Naturally producers find themselves paying premiums for actors who are not qualifying for the coverage.

On the bright side, the new system has begun making arrangements for HMO coverage and a prescription drug plan. HMO coverage has begun in many areas of the country, but not yet in New England (and there must be). Where it is available, the premiums to the producer are lower. Historically, the difficulty with this kind of medical plan has revolved around the fact that actors travel a lot to work away from home. HMO coverage, until recently, was not geared to this kind of "portability". But performers have unforeseen health needs that, while not an emergency nature, might affect their ability to work. Dancers need podiatrists or chiropractors, singers need throat specialists, etc.. While progess is slow, I think inroads are being made.

What we really need- all of us- is National Health Care for everybody. It is essential that unions, employers, government officials- all of us, continue to work to that end. It is every bit as essential to the citizens of this country as the education we are all guarantedd. Of course it isn't going to be perfect, and changes will have to be made. But we must start.

To: ARTIST HEALTH CARE TASK FORCE

From: CHRISTOPHER HARDING, Ph.D. (Playwright, Journalist)

3-30-94

As a person with an often misunderstood orphan disease, I have found my life-path channeled by the need to conform to free health care parameters rather than by the promptings of artistic self-expression.

Though I was trained to teach English and drama on the university level, my academic career abruptly ended when I belatedly manifested Gilles de La Tourette syndrome, a rare chronic brain illness characterized by seizures and involuntary muscle and verbal tics. Because I began to black out and exhibit strange behavior such as making pawing motions or scratching my throat until I drew blood during class, my contract to teach college courses was "not renewed" at institutions where I had taught for as long as10 years. I began to rely for my income on doing lower-paying, more time-consuming activities like writing for television, radio and print, directing community theatre productions, and writing plays, particularly the lyrics and book for musicals.

Writing permits the flexibility to work at those times when I feel able and free to work. My condition has entailed over 5 years of weekly and biweekly doctor visits, trying to find the right combination of drugs and therapy to minimize the effects of a condition that can not be cured. Drug trials often leave me dizzy, sleepy or unable to focus on intellectual and creative activity. Furthermore, the frequent doctor visits and lab tests create awkward

gaps in my time so that it would be difficult to hold down a 9-to-5 job even if I could concentrate for those hours.

Because I have absolutely no health insurance, I was able to qualify for full free outpatient care at Massachusetts General Hospital. For the past 5 years, I have availed myself of their psychopharmocological, psychiatric, pulmonary and internal medicine services, which would otherwise cost me about $500 a month, exclusive of lab tests. I pay for all medications out of my own pocket averaging about $150 a month. Grateful as I am for the care I receive, I am in a constant state of anxiety because the free service must be applied for and re-approved every six months.

Doctors spectaculate that a head injury I sustained while working in the theatre may have precipitated the manifestation of the condition. (I was struck in the forehead with a lead pipe while unloading scaffolding to build a set and had to be rushed to the emergency room. I still have the "dent" in my head.) Adding to my brain problems, my lungs were damaged in a chlorine gas explosion; I battle bronchial problems several months each winter. The periodic loss of my voice during this time of year interferes with my duties as an arts reporter on radio and television.

While Greater Boston Legal Aid managed to get me some disability money for my condition in 1990, at the beginning of 1993, the Social Security computer spit out a letter, announcing that it had been determined that I had never been eligible for this money. Social Security cut off my disability monthly check and my Medicaid insurance and demanded the return of the over $20,000 the government had paid over the past three years.

For over a year, I have been engaged in a legal battle to get this "overpayment" decision reversed and my disability funding reinstated, filing appeals and reapplications. Recently, I established that I am currently partially disabled by Tourette's, but I still have the $20,000 overpayment debt hanging over my head and no Medicaid.

Insecurity about continuing free care at Mass General and the feeling that government financial support is precarious at best aggravates my already strained mental and emotional condition. Free service even at as fine an institution as Mass General severely limits which doctors I can consult. This restriction is particularly unfortunate given the very imperfect understanding that medicine has of this brain disorder.

In order to continue to receive those services I have managed to secure, I don't dare look for work in another city or at pay level that puts me out of the eligibility range. Tourette's is a "pre-existing condition" that insurance companies do not want to touch. It may get worse as I get older. Even another slight head injury, which could come from a seizure, could change the way symptoms manifest themselves. It all feels like a colossal catch-22; it's hard to make the wisest strategy and self-care choices when your complaint relates to the brain and you don't have normal verbal and motor control.

Art provides a blessed outlet for these exasperating and frightening conditions. Therapeutic as the release may be, it can only distract me temporarily from the constraints of the disease, the side-effects of an ever-changing array of pills and distressing worries about the future.