PHOTOCOPY
PRESERVATION

LONG TERM CARE

long-term care

BACKGROUND ON PROBLEMS AND POLICIES ON LONG TERM CARE

GENERAL BACKGROUND ON OLDER AMERICANS

Today's elderly are healthier than ever before.

- **Today's elderly.** About 34.3 million Americans are age 65 years or older. Of them, 4 million are over the age of 85 and 386,000 are age 95 or older. About 60 percent of the elderly and over 70 percent of the people age 85 and older are women (U.S. Census, 1998).

- **Life expectancy is longer**. Today's elderly are expected to live more than 20 percent longer than the elderly in the early 1960s (NCHS, 1998). Since 1940, life expectancy at birth has increased from 63 years old to 76 years old (CDC, 11/10/98).

- **Today's older Americans are healthier than ever before.**
  - -- It appears that chronic illness among the elderly has declined -- 1.2 million fewer elderly are disabled than would have been if trends had continued (Manton, 1996).
  - -- The proportion of the elderly reporting fair to poor health status declined by nearly 10 percent since 1987 (NCHS, 1998). Hypertension among the elderly has dropped by about 20 percent among the elderly since the early 1960s (NCHS, 1998).

However, even while the proportion of elderly with health problems declines, the sheer number of elderly is skyrocketing.

- **In the year 2000, older people will outnumber children in the world for the first time in history.** (Secretary Shalala, on the announcement of 1999 International Year of Older Persons, 10/19/98) [note: not true in US]

- **The number of elderly will double by 2030.** The number of people age 65 years or older will double by 2030 (from 34.3 to 69.4 million). This is an increase from 13 percent of the general population to 20 percent of all Americans. The number of people 85 years or older will grow even faster (from 4.0 to 8.4 million) (U.S. Census, 1998).

- **Although getting healthier, the elderly are less healthy than younger people**.
  - About 55 percent of elderly women have arthritis, compared to 40 percent of elderly men and 23 percent of people ages 45 to 64. Over half of all people age 75 or older have arthritis (NCHS, 10/98).

- Of the elderly, about 13 percent have diabetes (22 percent of elderly African Americans), over 30 percent have heart disease (nearly half of all people with heart disease), 40 percent have high blood pressure (NCHS, 10/98).

- Nearly three-fourths of all deaths in 1996 occurred among the elderly (CDC, 11/10/98).

- **The number of seniors with chronic diseases is expected to increase by 100 percent over the next several decades** (HHS Fact Sheet, 10/14/98).

BACKGROUND ON LONG-TERM CARE NEEDS

- **What is "long-term care."** People with chronic illness or disability not only need regular health care services, but often require assistance in managing their health conditions and performing basic tasks such as eating, bathing and leaving their homes to go to the doctor.

  - "Formal" long-term care is paid long-term care services provided by health providers. It mostly consists of nursing home care and home health care.

  - "Informal" long-term is less skilled, unpaid care provided by people other than health providers -- family or friends. It consists of activities such as assistance with changing feeding tubes or monitoring medications, and providing help in dressing or going to the doctor.

- **What causes the need for long-term care**. A wide range of diseases and disabilities can result in long-term care needs. As such, people are classified as having long-term care needs if their chronic illness or disability results in limitations in their activities (e.g., eating, toileting, transferring, bathing, dressing, and continence management). Conditions that typically require long-term care include: diabetes, heart disease, arthritis, Alzheimer's disease and other dementias.

WHO NEEDS LONG TERM CARE

- **Millions of Americans of all ages have long-term care needs**. Nearly 2 million Americans live in nursing homes and another 4 million Americans live in the community but have health problems that would qualify them for nursing home care (need assistance to perform at least 3 of 6 basic activities of daily living). (ASPE, 1998)

  - About two-thirds of people with long-term care needs are elderly.

  - Nearly half of all people age 85 and older need assistance with everyday activities.

- Almost 1 million elderly people are severely cognitively impaired because they have Alzheimer's disease or another form of dementia (HHS, 1998).

- **Older women are more likely to have long-term care needs**. Women are 50 to 75 percent more likely to need long-term care, even after controlling for the larger number of elderly women, (HHS, 1998)

HOME & COMMUNITY-BASED LONG-TERM CARE

Three-quarters of the elderly with long-term care needs live in the community

- Over 70 percent of the elderly with long-term care needs lives with a spouse or other adult. Over 95 percent of them receive unpaid help from their spouse, son, daughter or other adult. Of these people receiving informal long-term care, only 40 percent also receive some paid health (e.g., Medicare home health visit) (ASPE, 1998).

- About 30 percent of the elderly with long-term care needs live alone. These elderly are much more likely to rely on paid assistance (60 percent versus one-third of those living with a spouse and other adult) (ASPE, 1998).

A large network of family and friends provides informal long-term care for people with long-term care needs at all ages.

- **Over 52 million Americans -- one in three -- voluntarily provide unpaid informal long term care each year to one or more ill or disabled family members or friends.** (HHS, 1998)

- **Families and friends provide a major amount of long-term care.**
  - 38 percent of informal caregiving is provided by adult children for their parents.
  - 11 percent is provided by spouses, usually among elderly couples.
  - 7 percent is provided by parents to significantly disabled children.
  - 20 percent is provided to other relatives (e.g., grandparents, aunts or uncles).
  - 24 percent is provided to friends or neighbors.

- **Most informal caregivers are women**. Women are nearly 30 percent more likely to be informal caregivres. Women provide about 50 percent more hours of informal care per week than their male counterparts. Black women are more likely to provide informal care than white women. (HHS, 1998)

- **The majority of informal caregivers work** (65 percent). Women who work full time provide an average of 11 hours of long-term care a week. (HHS, 1998)

People caring for <u>elderly</u> relatives or friends provide more, intense assistance.

- **Over 7 million Americans provide nearly 30 hours per week of assistance to elderly people with long-term care needs.** Typically, more than one relatives or friends help to care for these people (HHS, 1998).

- **Over two-thirds of primary caregivers live in the same house**. The majority of caregivers for the elderly with long-term care needs are spouses (40 percent) or adult children (36 percent) (HHS, 1998).

- **Caregiving often conflicts with work**. Two-thirds of working caregivers report experiencing conflicts that cause them to rearrange their work schedules, work fewer hours, or take an unpaid leave of absence from work (HHS, 1998).

- **Primary caregivers for the elderly are themselves older.** Their average age is 60 years old, and half are older than 65. About one third described their own health as "fair to poor." (HHS, 1998) This presents problems since informal caregiving often requires physical work like heavy lifting, frequent bedding changes, dressing and bathing (Feinberg, 1997).

- **Caregivers often have emotional as well as physical strains.** One study found that 68 percent of caregivers experienced depression (Feinberg, 1997). Women tend to experience higher levels of stress, even when controlling for their disproportionate caregiving role (Rose-Rego et al., 1998).

    - **Especially true for families caring for people with Alzheimer's disease**. Such caregivers experienced greater time demands, family conflict, strain, mental and physical problems, and financial hardship (Ory et al., 1998).

- **Despite the strain, nearly 70 percent of caregivers use positive words when describing how they felt about their role** (NAC/AARP, 1997).

- **Over 40 percent of family caregivers have household incomes less than $30,000 per year** (NAC/AARP, 1997).

- **Over 40 percent of people caring for elderly relatives also care for children under 18** (NAC/AARP, 1997).

- **Minority families tend to provide more informal care.** Controlling for level of disability, non-Caucasian caregivers provided more care than Caucasian caregivers (Tennstedt & Chang, 1998). The actual number of caregivers in minority families is higher than the number of caregivers in non-minority families, due in part, to the involvement of modified extended families (Chatters et al., 1998, 1986; Miller et al., 1994; Hatch, 1991; and Cox and Monk, 1990).

NURSING HOME CARE

- About 1.6 million older Americans and people with disabilities receive care in approximately 16,700 nursing homes. (HCF, 1998)

- 75 percent of nursing home residents are women. (NCHS, 1998).

- What worries people the most about growing old is having to live in a nursing home. Alliance of Aging Research.

- Nearly one in three seriously ill patients reported that they would rather die than end up in a nursing home.

WHO PAYS FOR LONG-TERM CARE

Total spending on long-term care

- **Direct medical costs for persons with chronic conditions** represent nearly 70 percent of national expenditures on health care. (HHS Fact Sheet, 10/14/98)

    - **Nursing home care**: Nursing home costs average over $46,000 per year. (Wiener & Stevenson, 1998)

- However, a large amount of long-term care, provided by family and friends, is uncounted. (Need stat on $$ for the health care system -- it is hundreds of billions each year that it would cost our health care system to provide the functions that family caregivers needs)

- **Few beneficiaries realize that Medicare does not pay for long-term care.** Although 63 percent of Medicare beneficiaries recognize that they are not covered for prescription drugs, only 44 percent of beneficiaries know that Medicare does not pay for long-term nursing home care. (Kaiser Family Foundation, 1998)

Medicaid

- **Medicaid is the largest insurer of long-term care in the nation**. It pays for two-thirds of nursing home residents, and 15 percent of home health care. However, it is a payer of last resort, covering the poor or those made poor by high health care costs. As with Medicare, Medicaid is unlikely to increase its coverage of long-term care since it already consumes a third of all Medicaid expenditures.

Private long-term care insurance

- **Little private insurance for long-term care.** Only 6 percent of the elderly and a very small percent of baby boomers have private long-term care insurance. This is because few businesses offer long-term care policies, they remain expensive, and few people recognize the need for this insurance.

- **Not the only answer.** Even if every baby boomer who could afford private insurance purchased it, less than one-third of long-term care costs would be paid for by private insurance in 2030.

Out-of-pocket spending on long-term care

- **Most long-term care costs are paid for out of pocket, by families.** About $25 billion was paid out-of-pocket on formal nursing home and about $6 billion on home health care in 1996. Long-term care expenditures account for nearly half (44 percent) of all out-of-pocket health expenditures for Medicare beneficiaries.

LONG TERM CARE AND OTHER AGING/HEALTH POLICY

- **Long-term care tax credit**. This proposal would for the first time give people with three or more limitations in activities of daily living (ADL) or their caregivers a tax credit of $1,000 to help pay for formal or informal long-term care. About 2 million people would benefit including over one million older Americans; over 500,000 people with disabilities, and approximately 250,000 children. This initiative also recognizes the invaluable, time, effort and caring of spouses and relatives make to housing, feeding and attending to the long-term care needs of these relatives with chronic illness as taxpayers who house a relative with long-term care needs can also receive this tax credit.

- **Family Caregiver Support Program.** This proposal creates a new national Family Caregiving Support Program to support Americans who care for chronically ill or disabled family member or friends. It would enable states to create "one-stop-shops" that provide critical information and counseling as well as respite services and adult day care. Approximately 250,000 families would benefit from caregiver counseling and other services that provide information about and assistance in receiving services critical to the task of providing personal assistance to a friend or relative. More than 76,000 will benefit from respite care provided at home, in an adult day care center, or over the weekend in a residential setting. (Investment: $140 million in 2000)

- **Educating Medicare beneficiaries about long term care options.** Medicare beneficiaries are often unaware of the fact that Medicare does not provide long term care services and have little information about the long term care options that best meet their needs. This proposal provides funds to HCF to launch a national education campaign to educate all of the 39 million Medicare beneficiaries about long term care options. (Investment: $25 million)

- **Offering private long-term care insurance to Federal employees.** Since expanding Federal programs alone cannot address the next century's long-term care needs, the Federal government -- as the nation's largest employer -- could serve as a model employer by promoting high-quality private long-term care insurance policies to its employees. OPM estimates about 300,000 participants would benefit from this program. (Investment: small administrative expenses)

- **Nursing home quality initiative.** This initiative would strengthen States nursing home enforcement tools and increase Federal oversight of nursing home quality and safety standards to assure that the 2 million Americans in nursing homes receive high quality care. [We also are considering creating a commission to examine ways to improve the quality of housing -- whether in nursing homes, assisted living arrnagements or other housing situations for the elderly and people with disabilities. (Investment: $116.5 million)]

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File long term care

I. CHANGING DEMOGRAPHICS

The number of people age 65 years or older will double by 2030 (from 34.3 to 69.4 million), so that one in five Americans will be elderly. The number of people 85 years or older will more than double (from 4.0 to 8.4 million). This means that millions of adults will have long-term care needs.

LONG-TERM CARE

- **Problem:** About 5 million Americans of all ages have significant limitations (cannot perform 3 or more activities of daily living without assistance) because of illness or disability and thus require long-term care. Nearly 2 million of these people live in nursing homes; the remainder live in the community. Many receive critical services in their community such as adult day care or home health or benefit from irreplaceable and uncompensated caregiving from countless relatives and friends.

  Millions of Americans provide care for family members with chronic illnesses or disabilities and studies suggest that the value of informal, unpaid long-term care provided by families is worth billions of dollars. While caring for a family member with long-term care needs can be some of the most valuable and rewarding work that Americans ever do, it often imposes difficult emotional and financial burdens. Two-thirds of working caregivers report experiencing conflicts that cause them to rearrange their work schedules, work fewer hours, or take an unpaid leave of absence from work. Most of the primary caregivers for the elderly are elderly themselves. Their average age is 60 years old, and half are older than 65.

- **Policy:** VP's policy is TBD but builds on the Administration multi-faceted policy to support Americans with long-term care needs and their caregivers that includes: (1) an $1,000 tax credit for Americans with long-term care needs or those who care for them; (2) a new National Family Caregiving Program that provides information and referral services as well as respite care (e.g adult day care, home health) for family caregivers); (3) A national campaign to educate Medicare beneficiaries on how best to prepare for and choose long-term care; (4) a proposal to have the Office of Personnel Management (OPM) serve as a model employer by offering quality private long-term care insurance to Federal employees; and (5) a Medicaid proposal that the VP unveiled in Tampa that enables states to choose home and community-based care without a waiver (helping undo the historical bias of the Medicaid program towards nursing homes).

- **Anecdotes:** The Vice President has hosted several forums around the country on long-term care this year and has met countless families caring for a loved one with long-term care needs. Whether it is an elderly parent or spouse or a child with a disability, the stories share similarities: family members report that caregiving is the most important work they ever do, but it is also the most difficult. Families often want to do everything

they can to keep their loved one in the community but often at tremendous personal expense (they give up jobs, compromise time with their children). They all report the critical importance of respite care. Richard Learned an active senior in Portsmouth told the VP about when he visited a woman who was caring for her mother and offered to watch her mother while the woman worked in her garden. The daughter said it was the first time she had anytime for herself in years. Another woman Jean Scarfo said that adult day care gives her a critical break from caring for her mother with Alzheimers and makes her a better caregiver.

MEDICARE

- **Problem:**

  Influx of Baby Boomers. As the elderly population doubles over the next three decades. Every respected expert in the nation recognizes that additional financing to the Medicare program will be necessary to maintain basic services and quality for any length of time. Without investing the surplus into the program, Medicare would have to grow at a rate at 60 percent below the per capita growth rate projected for the private sector.

  Need for a long-overdue prescription drug benefit. About 85 percent of beneficiaries fill at least one prescription a year for such conditions as osteoporosis, hypertension, myocardial infarction (heart attacks), diabetes, and depression. The vast majority of Medicare beneficiaries lack meaningful drug coverage. Only about 1 in 4 beneficiaries has retiree insurance which is the only real meaningful form of private coverage. Over 13 million Medicare beneficiaries have absolutely no prescription drug coverage. More than half of Medicare beneficiaries without drug coverage are middle class.

- **Policy:** The Administration has proposed a comprehensive plan to strengthen Medicare for the next century. It will:

  Eliminate the deductible and all copayments on preventive benefits covered by Medicare, including all cancer screenings, and diabetes management. These proposals are particularly important for Hispanic beneficiaries who are more likely to suffer from these conditions and less likely to be able to afford out-of-pocket costs.

  Provide a much-needed prescription drug benefit. Seventy-five percent of Medicare beneficiaries have unstable or inadequate prescription drug coverage. The Administration is proposing a new prescription drug option that is available for all Medicare beneficiaries. This proposal is particularly important to Hispanic beneficiaries who are less likely to have supplemental coverage. Hispanics would also benefit from the Administration's proposal to eliminate cost-sharing for the drug benefit for beneficiaries below 150 percent of poverty.

Secure Medicare for a Quarter Century. The Administration's proposal dedicates $374 billion to Medicare most of which helps extend the life of the Medicare Trust Fund until 2027 and makes Medicare more efficient and competitive.

Reduce the public debt. By locking away most of the surplus dedicated to Medicare, the Administration's proposal buys down the debt which helps boost national savings, leading to lower interest rates and a higher standard of living. Under the Administration's framework, the public debt will be eliminated by 2015.

Bad aspects of the Medicare proposals supported by Republicans: (1) Raises traditional Medicare premiums through a new premium support proposal which mostly produces savings by raising premiums for traditional Medicare; (2) Raises age eligibility to 67 which would increase the number of uninsured Americans; (3) Imposes new copayments for home care and nursing homes that cause higher out-of-pocket costs for some of the most vulnerable Medicare beneficiaries; (4) does not dedicate one dime of the surplus to strengthen Medicare

This effort builds on the Administration's long-standing commitment to the Medicare program. In 1993, the Medicare trust fund was set to expire by 1999. Now it is on track to remain solvent until 2015.

- **Anecdote:** The Vice President recently met Florence Seitz an 88-year-old woman from New Hampshire who pays close to $300 a month for prescriptions. One-third of that is for medicine she's supposed to take twice a day.``Sometimes I don't have the money and I cut it down to half," she said. ``Sometimes (doctors) have samples and I do all right on that."

HEALTH CARE COVERAGE

Current Administration Proposals:

Allowing Americans Ages 55 to 65 buy into Medicare.

- **Problem:** Americans ages 55 to 65 are the fastest growing group of uninsured in the country. . In the United States, there are about 21 million people ages 55 to 64. However, as the Baby Boom generation enters its 50s, both the number and proportion of pre-65 year olds will rise. As a result, the number of people between 55 and 64 years old is expected to increase to 30 million by 2005 and 35 million by 2010 — to 12 percent of the U.S. population, over a 50 percent increase. People ages 60 to 64 are nearly three times more likely to report fair to poor health as those ages 35 to 44. The probability of experiencing health problems such as heart disease, emphysema, heart attack, stroke and cancer is double that of people ages 45 to 54. The 3 million uninsured people ages 55 to 64 fall into three groups: workers, retirees, and non-workers.

- **Policy:** That is why Congress should pass our proposal to allow these vulnerable Americans to buy into the Medicare program. (specific policies include:

Helping People with Disabilities Get Health Care Coverage So They Can Return to Work.

- **Problem:** Access to health insurance is the biggest barrier for people with disabilities to return to work. They simply cannot get access to affordable health care coverage

- **Policy:** The Administration has proposed legislation (that is sponsored by Senators Jeffords and Kennedy and passed the Senate 98 to 0 but not yet the House) that allows people with disabilities to buy into the Medicare or Medicaid program.

- **Anecdotes:** In Albany New York, the Vice President was introduced by a woman (Maxcine Johnson) who suffers from MS and volunteers at the MS society. She desparately wants to return to work but cannot find access to affordable health care coverage that would cover her medical expenses and in particular the cost of prescription drugs that help manage her condition. In fact, she believes that "people with disabilities are the only Americans who want to pay more taxes."

Assuring that Children Have Access to Affordable Health Care Coverage.

- **Problem:** There are more than ten million uninsured children in America. There are four million uninsured children who are eligible for the Medicaid program but not enrolled.

  Compared with children who have insurance coverage, uninsured children have many unmet health care needs. They are more likely to be sick as newborns, less likely to be immunized as preschoolers, less likely to receive medical treatment when they are injured, and less likely to receive treatment for illnesses such as acute or recurrent ear infections, asthma, and tooth decay. (National Academy of Sciences, 1998) Uninsured children are also more likely to be hospitalized for conditions that could have been managed with appropriate outpatient care than insured children. (GAO, 1998)

  Insurance coverage is the major determinant of whether children have access to health care. 37% of uninsured children never see a doctor during the year, more than 2.25 times the rate for insured children. (Families USA, 1997) Children under the age of five go without routine preventive health care services at three times the rate of insured children. (Families USA, 1997)

- **Policy**: In 1997, the Administration fought for and enacted the Children's Health Insurance Program, the largest investment in children's health in the passage of the Medicaid program in 1965. Since then, the Administration has launched an aggressive outreach program to sign up the millions of uninsured children who are eligible for health insurance but not yet enrolled in the program.

New Al Gore Proposals:

Covering the Parents of Uninsured Children.

- **Problem:** There are currently seven million parents who have children that are either eligible for or are enrolled in the Children's Health Insurance Program or Medicaid. Most of these are working parents.

- **Policy:** This proposal would give states funding to expand health care coverage to the parents of children who are eligible for Medicaid or CHIP. States can expand coverage either through CHIP or Medicaid to parents up to 200 percent of poverty.

Helping Small Businesses Provide Affordable Health Care Coverage

- **Problem:** Workers in small businesses are less likely to have access to affordable health care coverage. Although workers in small firms make up about 30 percent of the workforce, they comprise nearly half of the uninsured. One-quarter of private sector workers in firms with fewer than fifty employees lack health care coverage. Small employers report that high premiums, the uncertainy in premiums and administrative costs are the major reasons why they do not offer health care coverage. Their administrative costs can be as high as 30 percent of their premiums – more than six times as high as many firms administrative costs.

- **Policy:**

Tax Credits for Individuals Without Access to Employer-Sponsored Coverage.

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Helping the uninsured.

PROGRESS AND PERILS

- **Progress**

- **Policy**

- **Perils:** Despite the fact that so much progress has been made need to assure that this progress is used to benefit patients and improve health – not to discriminate against

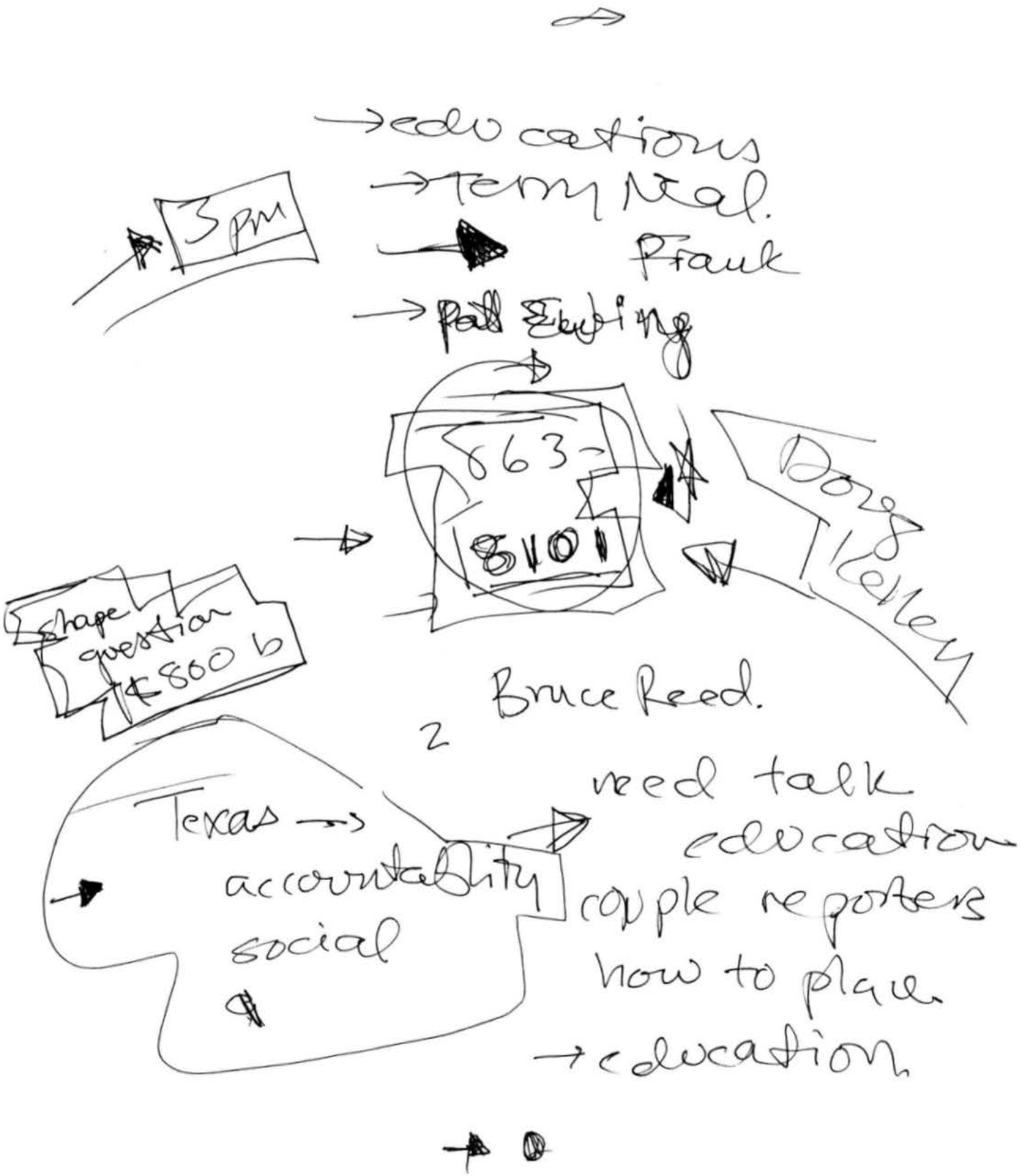
patients. For example, we know that a leading reason why women do not get the new breast cancer test is that they worry this information will be used against them by employers or insurers.

- **Policy:** That is why we have proposed legislation that prevents health insurers and employers from inappropriately using genetic information

- **Perils:** We also know that information that is now easily available by third party payors.

- **Policy** That is why we have proposed to comprehensive medical privacy legislation to assure that insurers. And if Congress does not act, we will do everything possible administratively to assure fairness for patients.

IMPROVING QUALITY IN THE HEALTH CARE SYSTEM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