Chapter 4

Willingness to Pay

The willingness-to-pay method of estimating the cost of injury is conceptually different from the human capital approach presented in Chapter 3. Human capital refers to individual worth measured by the production over time of a stream of output estimated at market value. Willingness to pay, on the other hand, reflects the value placed on health and life by individuals. Willingness-to-pay research is an effort to derive social preferences regarding public policy and assess the burden of pain, suffering, and loss in quality of life associated with injury. Thus, the willingness-to-pay method attempts to value life comprehensively.

Societal cost, according to the willingness-to-pay approach, has two components: 1) individual willingness to pay defined as the value a typical person places on health and safety, and 2) the cost the rest of society saves by preventing or controlling an injury. This chapter focuses primarily on the first term, how much people are willing to pay, and actually do pay, for safer and healthier lives. The second term, the savings society gains through injury prevention and control, includes increased tax revenues; reduced transfer payments in Medicare, food stamps, unemployment compensation, etc.; reduced private insurance payments; and reduced costs for administering transfer payment and insurance programs (Miller, Brinkman, and Luchter, 1988; U.S. NHTSA, 1983).

To Reduce Fatal Injury Risk

The literature on individual willingness to pay as a measure of the value of human life has grown in recent years. Some works are theoretical (Cropper and Sussman, 1988; Mishan, 1988; Rosen, 1988; Smith, 1987); some are philosophical (Administrative Conference of the United States, 1988; Gillette and Hopkins, 1988; Menzel, 1986; Merkhofer, 1987; Miller, 1988; Robinson, 1986; Viscusi, 1986; Wenz, 1986); and others are empirical (Blomquist, 1988; Fisher, Chestnut, and Violette, 1989; Garen, 1988; Gerking, de Haan, and Schultze, 1988; Hammitt, 1988; Moore and Viscusi, 1988). Miller (1989) evaluates 49 studies on this issue and concludes that 29 are of reasonably good quality. The most common problems with the remaining studies are: 1) faulty surveys, such as asking about probabilities too small for people to understand, restricting respondents to a few students or professors, or ignoring responses of zero; and 2) use of inaccurate risk variables, such as a variable on risk by industry that ascribes the same risk to the janitor, the secretary, and the machinery operator, or a variable on risk by occupation that was based on only one year of data and involved more occupations than deaths, thus causing most occupations to have equal risks of zero rather than varying, small levels of risk.

The 29 studies of good quality have estimated the values of a reduction in individual risk of fatal injury or illness based on four possible elements:

- Extra wages received for risky jobs;
- Price and demand for products that increase health and safety;
- Personal tradeoffs made between time, money, comfort, and safety; and
- Surveys about individual willingness to invest money to increase health and safety.

Miller converted the estimates from the 29 studies to 1985 after-tax dollars and recomputed those that involved a discount rate or value of time using consistent values for these parameters. Following the Blomquist method (1982),Miller also adjusted the values obtained to assure that behavior be interpreted in terms of perceived, rather than actual, risk levels. Table 24 shows the value of life by type of study.

Across the 29 studies, the individual willingness to pay to save one life ranges from $1.0 million to $3.1 million, with a mean of $1.95 million and a standard deviation of $0.5 million. This level of uncertainty is typical of the effectiveness estimates in most cost-benefit analyses. Furthermore, the emergence of values in a similar range from studies using many different approaches and data sets suggests that the methodological concerns raised by individual studies are not of central importance. For example, existing data appear to underestimate the risk of fatal workplace injury. A comparison across studies implicitly assumes that the willingness to pay to avoid death is the same for slow, painful death as for sudden death, and that the willingness to pay to reduce risk does not vary significantly between unavoidable risks like nuclear disaster and risks like auto crashes, over which the individual has some control. In addition, the choice for some workers may be between a risky job and unemployment rather than a less risky, but lower-paying, job.

To give a simple example of the estimation of the value of human life, a study might estimate that the average person spends $200 on optional auto safety features that reduce the chance of dying prematurely by 1 in 10,000. Dividing $200 by the 1 in 10,000 probability

Table 24

Individual Willingness-to-Pay Estimates of Value of Life by Type of Study, 1985

Type of Study **and** Sources	**Amount (millions*)**
Average of 29 Studies	$ 1.95
Extra Wages for Risky Jobs (15 studies)	1 .00-3.00
Demand and Price	
Safer cars (Winston & Mannering, 1984)	1.90
Smoke detectors (Dardis, 1980)	1.00- 1.80
Houses in polluted areas (Smith & Gilbert, 1984)	2.30
Life insurance (Landefeld & Seskin, 1982)	1.10
Behavior	
Pedestrian tunnel use (Melinek, 1974)	1.80
Safety belt use (Blomquist, 1979; 1988)	1.30-3.10
Speed choice (Jondrow, Bowes, & Levy, 1983)	1.30-1.60
Driver's travel time (Miller, 1989)	1.00- 1.20
Surveys	
Cancer (Landefeld, 1979)	2.40
Safer bus (Jones-Lee, Hammerton, & Phillips, 1985)	2.60
Safer job (Gegax, 1984)	2.00
Auto safety (Viscusi, Magat, & Huber, 1989)	2.20

Source: All estimates from Miller, 1989a; references in parentheses show primary sources prior to adjustment or value extraction from behavioral models

* After-tax dollars

suggests that the average person is willing to spend $2 million to assure a safe and healthy life. This value estimation does not imply that most people would actually be able to pay $2 million to avoid dying prematurely. The estimate is based on the small amounts people regularly pay – in dollars, time, discomfort, and inconvenience -- to reduce health risks. The aggregate expenditure of $2 million on health and safety, by ten thousand people, prevents one anonymous, statistical individual from dying. That is the price average Americans pay for safety.

To Reduce Nonfatal Injury Risk

The $1.95 million value per life is based on the behavior of people who have an average of roughly 40 years to live. If the net present value of 40 future life years is $1.95 million, the implied value per life year is roughly $120,000, based on a 6 percent discount rate. Willingness to pay to prevent a nonfatal injury can be estimated by multiplying this value times the years of functioning lost to injury, discounted to present value.

The percentage of functioning lost to different types of moderate and severe injuries has been estimated by a small number of physician experts (His et al., 1983). The ratings cover three time periods: the year after the injury, the second through fifth years, and thereafter. They examine six aspects of functioning: physical dependency, mobility, pain, and cognitive, cosmetic, and sensory functioning. Subsequently, the ratings were extended to a more comprehensive range of injuries (Carsten, 1986). Aided by the *Guides to the Evaluation of Permanent Impairment* (AMA, 1984), developed by physician panels of the American Medical Association, Carsten also developed a method for combining the ratings by functional aspect into a summary impairment rating. Luchter (1987) used the physician ratings to compute average impairment by injury severity, based on the relative incidence by severity of different injuries in auto crashes.

Table 25 shows estimates by injury severity of individual and societal willingness to pay to prevent nonfatal injuries. The societal amounts range from $30,000 for prevention of an injury of moderate severity to $1.5 million to prevent a critical injury. To prevent a fatal injury, the societal amount is estimated at $2 million. Thus, the willingness-to-pay estimates for reduction in critical nonfatal injuries and fatal injuries are roughly 4.5 to 6 times the cost per death caused by injury -- $317,187, estimated by the human capital approach.

To Avoid Specific and Minor Injuries

Arthur (1981) presents a theoretical model of willingness to pay that is readily extended to nonfatal events. The model indicates that willingness to pay to reduce the incidence of an injury equals willingness to pay for life times the relative loss associated with the injury and

Table 25

Individual and Societal Willingness-to-Pay Estimates for Reduction of Nonfatal Injury by Severity, 1985

Injury Severity	Individual (thousands*)	Societal (thousands*)
Nonfatal Injury		
Moderate	$25	$30
Serious	100	**115**
Severe	260	375
Critical	**1,225**	**1,525**
Fatal Injury	1,950	2,000

Source: Miller, Brinkman, and Luchter, 1988

* After-tax dollars

with death. The extended model was used to determine willingness to pay to prevent selected injuries and to assess the reasonableness of the values obtained from the physician ratings.

The medical decision-making literature is rich in scales that score the relative loss associated with different levels of health status. Some articles focus on chronic conditions -- for example, the loss due to a heart attack, hearing impairment, or kidney failure. Others create functional ability indexes or scales and score the relative loss at each point on the scale. The scores indicate total loss, including family loss in quality of life and pain and suffering, as well as financial loss.

Selected injuries were scored on several scales of reasonable quality, and the median loss across scales was used to estimate willingness to pay. On all the scales, the loss score for death was one, while the score for perfect health was zero. Scores were estimated for three groups of injuries: fates worse than death, serious injuries preferable to death, and minor injuries.

Fates Worse Than Death

Severe head injury, severe burns, and quadriplegia are examples of fates many people consider worse than death. Indications that people feel some fates are worse than death are easy to find. American slang is filled with such phrases as “He’d be better off dead,” or “I’d rather die.” Mercy killing is a hotly debated issue. The suicide rate soars for people **with** central nervous system disorders or AIDS (Marzuk et al., 1988). The largest jury awards have been primarily for severe injury, rather than death. The question of whether death or paralysis from the neck down is worse generally yields split, but emphatic, opinions.

Guilt, regret, stress, loneliness, bereavement, and pain can be much worse than death. The stressful uncertainty faced by the loved ones of a permanently unconscious person can exact a terrible cost. Three studies outlined below provide adequate information to assess the loss associated with fates generally considered worse than death.

Through sample surveys in Canada, Torrance (1982) developed scores according to status on four dimensions of functioning (mobility and physical activity, self-care and role function, emotional well-being and social activity, and health problems). He obtained further insight into fates worse than death by asking parents whether it would be better to bear a disabled baby or experience a still birth. One weakness of the health problems scale used by Torrance is that it has only one moderate level each for pain and disfigurement. Green and Brown (1978) surveyed British students about the relative severity of death and a variety of injuries.

Kind, Rosser, and Williams (1982) estimated scores on a two-dimensional health status scale. One dimension measures disability, with 1 representing full mobility and 8, unconsciousness. The second dimension measures distress, with 1 being none and 4, severe. Median scores were computed from the noneconomic component of British jury awards, which follow an informal schedule.

The loss scores for quaciriplegia and head injury resulting in long-term unconsciousness or total permanent disability were taken directly from the studies. Quadriplegia scores averaged about a 10 percent greater loss than death, while totally disabling head injury scores averaged about a 15 percent greater loss.

An important caution about these loss scores is that values vary widely among individuals. For example, Torrance (personal communication, 1988) found that partial and complete quadriplegics who adjust to their injury perceive their loss as 65 percent, while quadriplegics who sue for the right to starve to death clearly perceive a loss exceeding 100 percent. The 110 percent loss estimate for complete quadriplegia is an average loss score based on a survey of people with differing expectations about their ability to adjust.

The losses associated with severe burns were computed from the functional scales based on the impairment ratings reported by His and associates (1983). The physician ratings suggest that severely burned people over 45 generally would need an attendant for the rest of their lives, be confined to bed, and experience some mental impairment, as well as substantial disfigurement and pain. Severe burns are essentially the worst fate possible, with a loss almost 40 percent greater than the loss associated with death. It is little wonder that the debate over death with dignity is becoming more heated as the survivability of persons with these injuries and other severe health conditions increases.

Severe Injuries Preferable to Death

Functional scales were applied to paraplegia and partially disabling head injury, as was a scale developed by Kaplan (1982). Based on sample surveys in the U.S., this scale assumes no fate is worse than death. The scale has three dimensions (mobility, physical activity, and social activity) and adjustments for a diversity of symptom-problem complexes. It includes adjustments for pain by body part (at a single severity level) and for information related to disfigurement.

On average, complete paraplegia is associated with about a 60 percent loss, incomplete paraplegia about a 50 percent loss, and incomplete quadriplegia about a 90 percent loss. Torrance (personal communication, March 1988) reports that paraplegics who have adjusted well to the condition rate their loss at about 45 percent. Partially disabling head injuries are associated with losses ranging from 15 to 62 percent, depending on the severity of long-term consequences.

Miller and associates (1988) used the loss scores for serious burns, head injuries, and spinal cord injuries to validate selected willingness-to-pay estimates. They estimated individual willingness to pay to avoid critical injury at 1.1 million, which is on the same order of magnitude as the 1.2 million computed in Table 25 from the Carsten (1986) estimates of impairment and life years lost. The estimated willingness to pay to avoid a severe injury is $310,000, compared to the $260,000 computed from the impairment estimates.

Table 26 shows the estimated societal willingness to pay to avoid selected injuries. The highest amounts result from severe nonfatal injuries, rather than fatalities. Included is an estimated $3.6 million to avoid a severe burn, $2.9 to $3.2 million to avoid a totally disabling head injury, and $2.2 to $2.6 million to avoid injury resulting in quadriplegia. The estimate exceeds $1.3 million to avert an injury resulting in complete or partial paraplegia.

Minor Injuries

Physician ratings of functional impairment were not available for minor injuries. Data from the National Highway Traffic Safety

Table 26

Societal Willingness-to-Pay Estimates to Avoid Selected Injuries by Nature of Injury, 1985

Nature of Injury	Amount (thousands*)
Severe Head Injury	
Total impairment	$2,900-3,200
Partial impairment	550-1,500
Quadriplegia	
Complete	2,600
Partial	2,200
Paraplegia	
Complete	1,800
Partial	1,350
Very Severe Burn	3,600
Minor Injury	4
Death	2,000

Source: Miller, Brinkman, and Luchter, 1988

* After-tax dollars

Administrations National Accident Sampling System (NASS) indicated that an average of 2 days were spent in the hospital and another 2.8 days of ability to perform work or housework were lost (Miller et al., 1988) Perhaps another 4.8 days of progressively less severe activity limitation and mild pain might follow. The three impairment scales described above suggest an average functional loss of 37 percent for 9.6 days, or a total of .01 life years lost. The societal willingness-to-pay amount to avoid a minor injury is estimated at $4,000.

Conclusion

Much of this report discusses the cost of injury to society. This chapter focuses on a methodology that combines individuals' assessment of the amount they are willing to spend on injury risk reduction with the potential savings to society. This assessment yields values of $2 million to avoid death. To avoid moderate to critical injuries, the estimates range from $30,000 to $1.5 million. To avoid severe head injuries involving total impairment, quadriplegia, or very severe burns, willingness-to-pay estimates range from $2.6 million to $3.2 million.

There is support in the economics profession for employing the willingness-to-pay method rather than the human capital approach when a dollar value is placed on health and safety benefits in cost-benefit analyses or resource allocation models (Bailey, 1980; Menzel, 1986; Mishan, 1988; National Safety Council, 1987; Thompson, 1980). Regulatory analyses performed by several federal agencies have employed the willingness-to-pay approach. Included are the Consumer Product Safety Commission, Occupational Safety and Health Administration, Federal Highway Administration, Coast Guard, Federal Aviation Administration, Nuclear Regulatory Commission, and Environmental Protection Agency. The Department of Agriculture has also used the approach in cost-benefit analysis.

The American public would be willing to invest $300 billion a year to prevent all injury deaths and $800 billion to prevent all nonfatal injuries, for a total of $1.1 trillion. It is clear that the human capital approach yields significantly lower estimated values of human life than does the willingness-to-pay method. Both sets of estimates are presented in this report to provide the reader with the best and most current estimates available employing each approach.

Chapter 5

Potential Savings from Injury Prevention

The premature deaths, disabilities, and costs resulting from injury, including large public sector expenditures, highlight the need to reduce the burden of injury in the United States. The application of current knowledge can substantially reduce the incidence or severity, and accompanying cost, of injury. This chapter provides examples of estimated savings to society of selected injury control interventions for which reasonable estimates of effectiveness and cost can be made. When effects of an intervention are known, but data are insufficient on cost or current extent of implementation, the missing data are noted.

The precision of the estimates varies depending on research design and the generalizability of research findings. Scientists often disagree on these issues. However, in cases with large effects, or small effects based on large samples, it is unlikely that additional research would reverse the conclusion that a given intervention did or did not produce savings. In many cases, better data would increase the precision of the estimates.

Background

Some progress has been made in reducing injuries in the United States. Automobile occupant fatalities per million miles driven were reduced about 40 percent by the Federal Motor Vehicle Safety Standards authorized by the Motor Vehicle Safety Act of 1966 (Robertson, 1984). In New York City, where most children's deaths from falls result from crawling out of windows in multistoried buildings, health department initiated programs and regulations helped reduce such fatal falls of children from about 50 per year in the 1960s (Bergner, Mayer, and Harris, 1971) to about 4 per year in the 1980s (Bergner, 1982).

Numerous interventions to reduce the incidence and severity of injury have been identified (e.g., Haddon, 1970; Dietz and Baker, 1974; Robertson, 1983; Baker, O'Neill and Karpf, 1984; Waller, 1985), but many have yet to be implemented. Delay in the application of interventions known to be effective has a long history. In the 19th century, railroad workers had a very high injury mortality rate because of dependence on time tables to avoid the collision of trains on the same track, lack of uniform braking of all cars, and use of flexible chains to join cars. Despite the availability of automatic signaling systems, automatic braking systems, and automatic coupling systems in the 1870s (Adams, 1879), most railroads did not adopt the technology until it was required by Congress near the turn of the century (Robertson, 1983). Fatalities per thousand rail workers were reduced 80 percent from 1890 to 1920 (Swain, 1980).

In recent years, argument over the cost of applying interventions has been a major factor in delay of implementation. Determination of the net savings to society if any one intervention were implemented depends on estimates of level of incidence reduced, the cost of injury severity reduced, the estimated cost of implementing or increasing the intervention, and the extent to which the intervention would be applied. Unfortunately, for most interventions that have been suggested or implemented to some degree, data on all these elements are unavailable.

Savings Estimation Method

The current review of the literature on injury control interventions suggests that, most often, the cost of the intervention is not known or reported. Researchers who evaluate the effects of interventions seldom include cost estimates of the interventions.

It is also difficult to find data on the extent of implementation of many interventions. For example, a controlled experiment in which parents in an experimental group were counseled regarding infant falls from tables, beds, etc. suggests that these falls can be reduced about 41 percent by physician warnings and counseling (Kravitz, 1973). To estimate the savings that could be realized' from expanding such counseling, however, data is needed on the current extent of counseling by physicians. No survey of physicians to determine the extent of such counseling and its cost is known.

The following data are necessary to calculate savings:

a. Number of injuries of given severity to which an intervention applies;
b. Cost of injuries by severity;
c. Proportion of each severity level reduced by the intervention;
d. Reduced costs = Sum of $a_i \times b_i \times c_i$ where i = each severity level;
e. Cost of applying or incrementing the intervention; and
f. Net savings = d - e.

It should be noted that this is not cost-benefit analysis. Certain costs and benefits that are not translatable into dollars are not included. On the cost side, for example, some interventions include alteration in transportation of teenage children that changes the daily routine of families. On the benefit side, for example, the human capital approach does not include reduced pain and suffering, and on the cost side, substitution of economic productivity with caregiving by family members. The willingness-to-pay approach includes the assumptions that people perceive risks accurately and evaluate them in economic terms. Even were the latter true, the public's assessment of many risks is at variance with reality (Slovic, Fischhoff, and Lichtenstein, 1987). Nevertheless, with assumptions explicit, application of a particular method to a variety of interventions sheds light on the relative merits of the interventions in economic terms.

Table 27 presents savings estimated for several interventions by the human capital and willingness-to-pay methods, separately, using data from Chapters 2 and 4. Although some of the uncertainties and ranges of estimates are discussed in this chapter, the literature cited should be consulted for a more complete view of the strengths and limitations of the studies relative to their use here. More detail on the methodology is found in Appendix B.

Table 27

Estimated Cost and Savings of Interventions to Reduce Injury and Severity

	Cost (millions)			Savings (millions)	
Intervention	**Human Capital**	**Willingness to Pay**	**Program**	**Human Capital**	**Willingness to Pay**
Child pedestrian injury campaign	**$112**	**$234**	**$54**	**$58**	**$180**
Bicycle helmet promotion	**255**	**356**	**72**	**183**	**284**
Driver education elimination	**-700 ***	**-2,067 +**	**-163 ***	**863 ****	**2,230 ****
License age 17	**1,446**	**4,267**	**0**	**1,446 ****	**4,267 ****
Motorcycle helmet use laws	**393**	**1,500**	**296**	**97**	**1,200**
Reduced ignition of cigarette paper	**187**	**1,100**	**0**	**187 ****	**1,100 ****
Air bags	**8,650**	**23,491**	**4,000**	**4,650**	**19,491**
Side crash protection	**916**	**3,529**	**2,000**	**0**	**1,529**
Automatic vehicle lights	**391**	**1,154**	**620**	**0 ****	**534 ****

*** Represents reduced cost**
**** Excludes savings in property** damage

Implementation Strategies

Implementation strategies can be categorized into four general approaches:

- Persuade individuals to reduce risky behavior or protect themselves and others;
- Require that people refrain from risky behaviors or increase protection by administrative rule or law;
- Change vehicles or environments to increase automatic protection (that is, the individual at immediate risk does not have to be changed to be protected); and
- Improve post-injury emergency and rehabilitative treatment services.

Generally, automatic protection is most successful and persuasion least successful, particularly if the persons at risk must take very frequent action for protection, such as the use of child restraints and safety belts in cars (Robertson, 1975). There seems to be a preference for education and other behavior-change approaches without resort to law, probably because they are thought to be less controversial or less costly, but such assumptions are subject to challenge by research. Laws may reduce risk if sufficiently enforced, but several nonlegal factors are related to both compliance with law and degree of enforcement (Robertson, 1983). The success of automatic approaches requires technical competence in design and quality control in implementation, after political, social, and economic barriers are overcome.

Persuaded Behavior Change

The research on three attempts at behavior change by persuasion is complete enough to allow a savings estimate – a campaign against child-pedestrian injuries tested in three cities, a bicycle helmet promotion tested on a large scale in Australia, and high school driver education, which has been the subject of numerous studies.

Campaign Against Child-Pedestrian Injuries

Based on research regarding child 'dart-out' behavior resulting in pedestrian injuries, a campaign using an animated character, "Willy Whistle," in schools and on television was studied in three cities. The researchers estimate a 20 percent reduction in dart-out injuries to pedestrians under age 15 and a 12 percent reduction in all child-pedestrian injuries. The one-time developmental and research cost of the campaign was $472,000. The success of the campaign is dependent on use in school classrooms and on television. The television time (e.g., 380 showings in Los Angeles valued at $150,000) was contributed by local stations as a public service (Blomberg, Preusser, Hale, and Leaf, 1983).

Apparently only Miami, Florida has used the program consistently. The Miami schools spend $95,000 per year to implement the program in 135 elementary schools, about $704 per school. If that cost is generalizable to the 76,000 elementary schools in the U.S., the annual cost of full implementation would be about $53.5 million per year, excluding any contributed television time. Limiting the use of the program to schools in neighborhoods that have a history of child-pedestrian injuries would reduce the cost. Since the effect of the program used only in schools without any television may be less than in the original experiment, the savings may be less with only school use.

There were 978 deaths to pedestrians under age 14 in 1985. Using ratios of deaths and hospitalizations to incidence of medically treated child-pedestrian injuries from a large regional study (Barancik, Chatterjee, Greene-Cradden, et al., 1986), investigators estimate the medically treated incidence and hospital admissions per fatality. A **12** percent reduction in child-pedestrian injuries would result in about 117 fewer fatal injuries, 1,413 fewer hospitalizations, and 2,289 fewer medically treated and released cases.

The cost of these injuries in human capital terms would be about $112 million, and by willingness-to-pay estimates, $234 million for fatal injuries alone. The human capital savings exceed the estimated cost of the program by about $58 million. Savings employing willingness-to-pay estimates less the cost of the program, would be about $180 million. The latter approach excludes nonfatal cases, for which the cost was not comparably calculated.

A film entitled “And Keep on Looking,” dealing with a wider range of child-pedestrian situations for 9-12 year olds, has been field tested and a 20 percent reduction in injuries estimated (Pruesser and Lund, 1988). A videotape combining the “Willy Whistle” and the new film is being considered for distribution to urban and suburban schools by the National Highway Traffic Safety Administration. If these tapes are used, they may provide substantial results at less cost per school than the Miami program, but the cost per school has not been established.

Bicycle Helmet Promotion

Head injuries to bicyclists can be reduced substantially by helmet use (Thompson, Rivara, and Thompson, 1989). A promotional campaign to increase use of bicycle helmets in Victoria, Australia during 1982-85 resulted in a 20 percent reduction in head injury to bicyclists (Wood and Milne, 1988). The campaign included:

- 1,000 helmets sold through the schools at two-thirds retail cost;
- Required helmet wearing while cycling in school activities;
- Poster distribution to all schools, physicians, and helmet retail outlets;
- Distribution of promotional materials to cycling clubs;
- A television and radio campaign that cost $A160,000 (Australian dollars); and
- Government rebates of $A225,000 to purchasers of about 25,000 helmets.

Although the total cost of this effort is not calculable, a reasonable estimate of the program cost, given the identified cost, is $A500,000. The cost to consumers of helmet purchases must be added to that amount. The helmets known to have been sold through the rebate program cost consumers about $A900,000 after subtracting the rebates. The total cost, not counting unrebated helmet purchases, was about $A1.4 million in a population of 3.9 million. To implement the program in the U.S. population of about 245 million, converting Australian dollars to U.S. dollars at the 1985 conversion rate, 1.208, would cost about $72 million, assuming comparable rates of bicycle use.

The total incidence and severity of head injuries to bicyclists is unknown. Head injuries have ranged from 49 percent to 67 percent of hospital admissions of bicyclists in three studies (summarized in Friede, Azzara, Gallagher, and Guyer, 1985). Assuming that these estimates are reasonably accurate, and applying the ratios of hospitalizations and deaths to incidence from a large regional study (Barancik et al., 1986), a 20 percent reduction in bicyclist head injuries would result in 178 fewer fatalities, 2,463 fewer hospitalized injuries, and 16,602 fewer injuries treated and released. Deducting the $72 million cost of the program, the savings of the Australian bicycle helmet program in the U.S. would be about $183 million in human capital terms or at least $284 million by willingness-to-pay estimates. The latter estimate is for fatality reduction alone since the nonfatal injury cost was not calculated in a way usable here. The validity of these estimates depends on the extent to which cultural differences affect public acceptance of such programs and on the extent to which the direct conversion of Australian and U.S. dollars distorts differential effects of incentives in countries with different wage structures.

Driver Education

One of the most widespread attempts to educate people to reduce injury by altering behavior is driver education in the public schools. According to the latest survey (1982-83), 998,363 students were enrolled. Costs per pupil varied widely among the states, but the median was $163 (National Safety Council, 1985). Therefore, high school driver education cost approximately $162.7 million in that year, not counting time diverted from academic subjects. The 1985 cost was probably not very different from the 1982-83 cost since any decline in numbers taking the course in the two years after the most recent survey would be at least partly offset by inflation in cost per pupil.

Unfortunately, the scientific evidence indicates that expenditures on driver education in the public schools had an adverse rather than an ameliorative effect on injury rates. Al though carefully controlled experiments find that driver education has little or no effect on individual risk in the aggregate (Shaoul, 1975; Lund, Williams, and Zador, 1986), it results in a large increase in licensure in an age group that has a very high crash rate (Shaoul, 1975). An increase of 8 licensed 16- and 17-year-olds per 10 students was found in a 27-state study (Robertson and Zador, 1978). In Connecticut, when driver education was eliminated from the public schools in nine school districts, there was a 75 percent decline in licensure of 16 and 17-year-old drivers of those taking high school driver education compared to comparable districts that retained the course (Robertson, 1980).

A 75 percent reduction in licensure of the 998,363 students enrolled nationally in 1982-83 would reduce the number of fatal crashes by about 595 per year based on the national rate of 7.95 fatal crashes per 10,000 licensed drivers aged 16-17. There were 1.64 deaths per fatal crash of 16-year-old drivers, so about 976 deaths can be attributed to early licensure due to driver education.

Since 16-year-old drivers have a fatal crash rate per mile about 11.4 times that of drivers aged 35-39 (Robertson, 1983), near the average age of their parents, there would be about 91 percent fewer deaths if parents drove their children the same number of miles that the children drive themselves. Therefore, adjusted for substitution of parental driving, the reduction from eliminating driver education would be approximately 0.91 x .75 x 976 or 666 deaths per year. If the distribution of nonfatal injury severity relative to deaths is similar to the distribution for all crashes, severity of injuries reduced would be distributed by the Abbreviation Injury Scale (AIS) as follows: AIS 1 - 69,657, AIS 2 - 5,974, AIS 3 - 1,325, AIS 4 - 213, AIS 5 - 71, fatal - 666.

The estimated savings of crash injuries prevented would be approximately $700 million in human capital terms or $2.1 billion by willingness-to-pay estimates had there been no driver education in public schools. Adding the savings from eliminating the program, the total savings would be about $863 million per year in human capital terms or $2.2 billion by willingness-to-pay estimates, not counting property damage.

Laws Addressing Individual Behavior

Estimates of savings from the effects of laws on individual behavior are not possible for many laws because the cost of enforcement is unknown. Estimates are attempted below for two cases -- legal driving age and motorcycle helmet use, for which the cost of enforcement is considered to be minimal.

Legal Driving Age

Driver education would have no adverse effect if the legal minimum driving age were raised to 18 (Robertson and Zador, 1978). Since no state has a minimum licensing age of 18, the exact effect of such a policy cannot be estimated. Research comparing fatal crash involvement of 16-year-old drivers in New Jersey with a licensing age of 17 (except for an agricultural license at age 16) and Connecticut with a licensing age of 16 indicates that about a 65-85 percent reduction in fatalities involving 16-year-old drivers would ensue from a minimum licensing age of 17 (Williams, Karpf, and Zador, 1983). Although the study found that the fatal crash rate involving 17-year-old drivers in New Jersey was slightly higher than in Connecticut, the fatal crash rate of drivers in the combined 17-29 age group was comparable among the states. Also, there were no offsetting rates of 16-year-olds killed as pedestrians or bicyclists.

In 1985, 2,014 people in the United States were killed in crashes involving 16-year-old drivers. Applying the same adjustments for parent substitution for 16-year-old drivers as in the case of driver education, about 1,375 deaths (0.91 x 0.75 x 2,014) would have been avoided if the legal driving age had been 17 in 1985. Assuming that the ratio of nonfatal to fatal injury distribution when these drivers are involved is similar to that for drivers in all age groups, the reduction in injury distribution of a 75 percent decrease in crashes by drivers less than 17 years old would be approximately as follows: AIS 1 - 143,808, AIS 2 - 12,344, AIS 3 - 2,736, AIS 4 - 440, AIS 5 - 146, fatal - 1,375. Since it is unlikely that every trip of a 16-year-old driver would be substituted by a parent or other adult, this is a conservative estimate.

A total savings of $1.4 billion in human capital terms or $4.3 billion by willingness-to-pay estimates would result from a minimum licensing age of 17. This does not account for time spent by parents or others transporting teenagers under age 17 or the savings in property damage. A survey of teenagers in Michigan, New Jersey, and New York, with very different rates of licensure, found very little effect of licensure on lifestyle. The increase in percent of teenagers with jobs, comparing employment at age 15 and 16, was highest in New Jersey, where licensure at 16 was prohibited except in agriculture (Preusser, Williams, and Lund, 1985).

Law enforcement expenditure would probably not have to be increased much, if any, to achieve the reduction. Most law enforcement would be achieved by parents who are unlikely to allow unlicensed drivers to use family vehicles.

Motorcyclist Helmet Use Laws

Laws requiring motorcyclists to use helmets reduce motorcyclist deaths by about 24-30 percent (Robertson, 1976; Watson, Zador, and Wilks, 1980; Hartunian, Smart, Willemain, and Zador, 1983). Data on nonfatal head injuries are sparse, but one study indicates that the increase in such injuries after repeal of a helmet law paralleled the increase in deaths (McSwain and Lummis, 1980). The nonfatal head injury to death ratio was 3:l.

The number of motorcyclist fatalities in states without helmet laws in 1985 was 2,714. Therefore, based on a 24 percent reduction from the law, it is estimated that 651 fewer deaths and 1,953 fewer head injuries would have occurred had these states had helmet use laws. The reduction in injuries and deaths multiplied times their cost, results in an estimated cost reduction of $393 million in human capital terms or $1.5 billion by willingness-to-pay estimates.

Such a reduction is particularly significant because it would disproportionately reduce public expenditures. A detailed analysis of the cost of treatment and rehabilitative care of motorcyclists in a major trauma center found that 63 percent of the costs were borne by the taxpayers, mainly through Medicaid (Rivara, Dicker, Bergman, Dacey, and Herman, 1988). This is in contrast to all motor vehicle injuries, for which about 19 percent of treatment and rehabilitative costs are paid by Medicare and Medicaid (U.S. National Highway Traffic Safety Administration, 1983).

Helmet use rates in states without laws range from 42 to 59 percent (Williams, Ginsburg, and Burchman, 1979). Assuming that about 50 percent of the owners of registered motorcycles in the states without laws would have to purchase a helmet, the cost of the helmets would be approximately $296 million (based on a median price per helmet of $170 in 1989, although some were available for less than $100). Assuming that the helmet would be used in subsequent years, the annualized cost would be a fraction of that amount. Since virtually all motorcyclists use helmets in states where there are laws, the increment in law enforcement cost is considered nil. Therefore, if motorcyclist helmet use were required in states without such laws, the savings, subtracting the cost of the helmets, would be about $97 million in human capital terms or $1.2 billion by willingness-to-pay estimates in the first year. Savings would increase in subsequent years because helmets would not have to be repurchased each year by most riders.

An earlier analysis of the net human capital losses from motorcycle helmet repeal, using more detailed age distributions but a lower estimate of helmet costs, put the net cost of repeal of helmet laws at $160 million in 1980 (Hartunian et al., 1983).

Product Design and Environmental Changes

Numerous potential changes in product design and environments have been studied. For many, the cost and effectiveness varies by degree since various levels of protection are possible. The examples below -- cigarette design; automobile air bags, side crash protection, and automatic lights and head restraints; and offshore drilling equipment -- are analyzed briefly at one specified level of protection each.

Reduced Ignition Potential of Cigarettes

The most frequent cause of housefires is a cigarette dropped on bedding or upholstered furniture where it smolders and later produces a killing smoke or fire, often after occupants of the household are asleep. In response to The Cigarette Safety Act of 1984, a Technical Study Group on Cigarette and Little Cigar Safety produced a report on the feasibility and the cost of modifying cigarette design to reduce the likelihood of ignition by dropped cigarettes (Technical Study Group, 1987).

Experimental cigarettes manufactured on equipment now used by the industry were tested on fabric, standardized as to padding and geometry. The numbers of ignitions in 20 tests varied from 0 to 20 for cigarettes with 41 combinations of type of tobacco, tobacco density, paper porosity, citrate added, circumference, and second paper wrapping. Lower ignitions were associated with low tobacco density, lower circumference, lower paper porosity, and no citrate added.

Subsequent tests on commercially available furniture with fabric and substrate similar to the standardized mockup produced an exceptionally strong correlation (r=0.86) to results with the mockup. Although the Technical Study Group cautiously called for more work to establish performance criteria, the results of these studies indicate that reliable tests of cigarettes for potential ignition are feasible and standards for cigarette manufacture could be based on performance in such tests.

Various costs and savings related to the modification of identified characteristics of cigarettes were estimated by a group at the National Bureau of Standards for the Technical Study Group (Ruegg, Weber, Lippiatt, and Fuller, 1987). A combination of modifications to cigarettes could achieve up to a 75 percent reduction in cigarette-related fire injuries, but several would result in increased cost of manufacture and lost revenues to farmers and in taxes. Reduced paper porosity, a modification that was assumed to generate no cost, produced a 30 percent reduction in ignitions. A 30 percent reduction in cigarette-ignited fires in 1985 would have avoided about 450 deaths and 2,100 injuries as well as millions of dollars in property damage. The cost of these deaths and injuries is estimated to be $187 million in human capital terms or $1.1 billion by willingness-to-pay estimates (excluding reduced property damage cost).

Air Bags

After 20 years of regulatory battles and court decisions, a federal standard now specifies limits for forces on the head, chest, and legs in frontal crashes of automobiles at 30 miles per hour into a barrier. The standard is being phased in during the 1987-1990 model years. Manufacturers have indicated that, to comply with the standard, some vehicles will have driver-side airbags and safety belts in the right-front seat. Others will have the automatic safety belts in driver and right-front passenger positions. Automatic safety belts vary in effectiveness depending on design and ease of detachability (Graham and Henrion, 1988; O'Neill, 1988).

Estimates of the effect and cost of various forms of compliance with an automatic restraint standard have been the subject of controversy for two decades. The official regulatory analysis indicates fatality reductions of 40-50 percent for fully used lap-shoulder belts, 35-50 percent for fully used automatic belts, and 45-55 percent for air bags with full lap shoulder belt use (U.S. National Highway Traffic Safety Administration, 1984). Since full belt use will not be accomplished, even with belt use laws and automatic belts, the actual effectiveness depends on projections of belt use generally and particularly among people at high risk. The effect on fatalities of increased use as the result of safety belt use laws is not nearly as high as predicted by estimated effectiveness of belts (Williams and Lund, 1988).

Eventually, as the relative effectiveness of the various technologies in actual use becomes known, the use of air bags will likely increase. Use of full front-seat air bags, assuming no belt use, is estimated to reduce deaths by about 6,190 (range -- 3,780-8,630); AIS 1 injuries, by about 255,770 (no range indicated); and AIS 2-5 injuries, by about 110,360 (range -- 73,660-147,560) (U.S. NHTSA, 1984). Since the midpoint of the range is the best estimate, it is used to estimate savings of approximately $8.7 billion in human capital terms or $23.5 billion by willingness-to-pay estimates.

Increased belt use would reduce these estimates to the extent that there is overlap in the injuries reduced by air bags and those reduced by belts. Belt use laws have increased belt use from 10-20 percent to 40-60 percent with an accompanying reduction in deaths of 5-15 percent (Williams and Lund, 1988). Some of that reduction is in side crashes and ejections that would not overlap with the effect of airbags.

Since about 10 percent of the U.S. fleet is replaced with new vehicles each year, the savings from a modification of vehicles over their average lo-year use is about the same as the cost of injuries in a given year minus the cost of modifying a cohort of new vehicles of a given model year. The charges for air bags by manufacturers have varied from $300 per car for full-front-seat air bags as an option by General Motors in the mid 1970s to $800 per car for driver-side air bags in certain recent models of several manufacturers. Like all vehicle components, the cost per unit is greatly reduced as a function of the number manufactured. The National Highway Traffic Safety Administration estimated $364 per car for full-front air bags, including lifetime energy costs of the added weight of the vehicle (U.S. NHTSA, 1984). Multiplied times the number of new cars sold in 1985 (11.04 million), the cost of full-front air bags on all cars would be about $4 billion. Thus, subtracting the cost of the air bags, full-front airbags in each model year would save about $4.7 billion in human capital terms or more than $19.5 billion by willingness-to-pay estimates.

Side Crash Protection

The National Highway Traffic Safety Administration is presently receiving comments on a proposed rule to increase protection to occupants of passenger cars hit from the side, which accounted for 32 percent of car occupant fatalities in 1985 (U.S. NHTSA, 1988d).The NHTSA analysis presents effects and costs of various degrees of protection. At the highest level of proposed protection, estimated injury reduction would be approximately: AIS 3-5 - 4,735, fatal - 1,200.

Since NHTSA did not estimate any benefits for reduction in AIS 1 and AIS 2 injuries, the savings of $916 million in human capital terms or $3.5 billion by willingness-to-pay estimates are conservative. The 'worst case' cost estimate of the proposed side protection is $185 per car, including lifetime fuel costs, or a total cost, if applied to new cars sold in

1985, of about $2 billion. Therefore, while it seems there would be no net savings in human capital terms at that level of protection, the savings by willingness-to-pay estimates, less the cost of increased side protection at the specified level, would be approximately $1.5 billion.

Automatic Vehicle Lights

Increased conspicuity of motor vehicles has been found an important factor in multiple-vehicle crash rates. Evaluations of the effects of the daytime use of headlamps, parking lamps, or redesigned systems have produced estimates of reductions in daytime, multiple-vehicle crashes of 7-38 percent (Stein, 1985). Sweden experienced a 11-13 percent reduction in such crashes when daytime headlamp use was required by law, despite the fact that 50 percent of drivers were using headlamps in daytime before the law (Transport Canada, 1986).

While crash reductions can be largely accomplished by requiring the driver to turn the lights on by law as was done in Sweden, there is substantial potential for adverse reaction from people whose batteries die when they forget to turn the lights off at the end of a trip. An automatic relay that turns the lights off when the ignition is turned off would alleviate this problem.

Although the current use of headlamps in daylight in the U.S. is unknown, it is unlikely to exceed 5 percent. Therefore, even considering the differences in weather and hours of daylight year-round between Sweden and the United States, the 11-13 percent reduction in crashes in Sweden, given a 50 percent prelaw headlamp use, seems a minimum to expect from automatic use were such a policy adopted in the United States.

Assuming that the nonfatal severity to death ratio in daytime multiple-vehicle crashes is similar to all crashes, a 12 percent reduction in daytime multiple-vehicle collisions in 1985 would reduce injuries approximately as follows: AIS **1 -** 38,907, AIS 2 - 3,337, AIS 3 - 740, AIS 4 - 119, AIS 5 - 40, fatal - 372. This amounts to $391 million in human capital terms or $1.2 billion by willingness-to-pay estimates, excluding property damage and pedestrian injuries that might be avoided by greater vehicle conspicuity.

Transport Canada estimates the lifetime cost per vehicle of automatic reduced intensity highbeams at $40 for cars and light trucks, including increased fuel use. Applied to the 15.5 million cars, light trucks, and vans sold in 1985, the lifetime cost of the lights would be about $620 million. Since the lifetime use of a given model year is about equal to that of the full fleet in one year, automatic lights on all new vehicles in a given model year, if only 12 percent effective, would produce no savings in human capital terms but would save about $534 million by willingness-to-pay estimates, after subtracting the cost of the lights. Using a human-capital cost method and including savings in property damage excluded here, Transport Canada concludes that the savings from automatic headlamps would be greater than the costs (Transport Canada, 1986).

Automatic Head Restraints

The federal standard for head restraints can be met by adjustable restraints or by high seat backs that automatically reduce neck injury in rear-end crashes. Despite the fact that high seat backs are probably less expensive and certainly more effective in reducing neck injuries, about 70 percent of new cars are equipped with adjustable restraints. High seat backs were found to reduce injuries by 17 percent compared to 10 percent for adjustable restraints and were said to cost $28 less per car (Kahane, 1982). Recently, the National Highway Traffic Safety Administration has revised its cost estimate, indicating little difference in the cost of the two types of restraints on average, but the cost is said to vary from $20 to $40 for adjustable restraints and $20 to $37 for high seat backs depending on materials used (U.S. NHTSA, 1988c).

A reduction of about 64,000 neck injuries in rear-end motor vehicle collisions occurred annually with a mix of 70 percent adjustable restraints and 30 percent high seat backs. If there were 100 percent high seat backs, the reduction would be about 85,000, a difference of 21,000. In 1981, neck injuries were estimated to cost about $670 per case, not counting pain and suffering (Kahane, 1982). Therefore, 100 percent installation of high seat backs would save approximately $14 million per year in injury cost, assuming no difference in the cost of the two types of seat on average.

Power Makeup Equipment in Offshore Drilling

In oil drilling, pipes are connected and disconnected by large tongs that work similarly to wrenches. Workers who handle the tongs experience a variety of injuries. Worker proximity to the mechanical energy in such operations can be altered by the use of ‘power makeup equipment.’ Comparison of sites with such equipment to those without, both before and after the installation of the equipment, indicates a reduction of 42 percent in related worker injuries per hours worked. The reduced cost of the injuries would pay for the equipment in 6 years (Mohr and Clemmer, in press).

Since the extent of such equipment use throughout the industry is unknown, the total savings to society if the equipment were installed at all offshore drilling sites cannot be estimated. Nevertheless, the case illustrates the principle that injury reducing equipment in industry can pay for itself in reduced injury costs and should be considered an investment rather than a cost.

Data Needed for Estimation of Savings

A list of some interventions for which data on effects have been estimated, but data on other aspects of savings analysis are unknown, is presented in Table 28. Many of the references for this section are in the table and are not repeated in the text. Although a large-scale literature review was conducted to find examples of interventions with known effectiveness, some may have been missed.

Missing Implementation and Cost Data

Counseling by physicians has been found to promote injury-reducing behaviors such as child restraint use and purchase of smoke detectors. In the study of pediatric counseling regarding infant falls from tables, beds, etc., counseling was associated with a 41 percent reduction in such falls compared to a control group that did not receive counseling. The extent and cost of the counseling and the severity and cost of the injuries are unknown.

Drownings associated with children wandering into unsupervised swimming pools occurred 65 percent less frequently in Honolulu, where pool fencing is required, than in Brisbane, Australia which had no such requirement. The cities have similar weather and pool to household ratios. While the cost per pool of fencing can be easily obtained, the extent of installed fencing of pools in the U.S. is unknown as is the distribution and cost of drownings and near drownings associated with the lack of fencing.

Motor vehicle fatalities and other health problems related to alcohol are lower in correlation with increased alcohol taxes, but taxes have not been raised to keep pace with inflation. Restoring the 1950 taxes on alcohol adjusted for inflation would increase the revenues generated by $20 billion per year (Hacker, 1987). Since both the severity distribution of injuries attributable to alcohol and the cost of administering the taxes are unknown, an estimate of the savings from increased alcohol taxes is not attempted here.

Although relatively nonsevere injuries must occur in substantial numbers to equal the cost of one very severe injury, such seemingly mundane injuries as fractures and other injuries from sliding into bases while playing softball are not without significant cost. A recent study estimated a cost of $1,223 per sliding injury. Use of breakaway bases reduced such injuries by 95 percent at a cost of $48 per base (Janda, Wojtys, Hankin, and Benedict, 1988). Without an estimate of the extent of the injuries and the use of breakaway bases nationally, however, savings from the universal use of breakaway bases cannot be calculated.

Administration and Enforcement Costs

Motor vehicle occupant deaths of infants (per 100,000 population in that age group) declined 37 percent from 1980 to 1984 in association with the enactment of child-restraint use laws. The reduction in 1980-84 for children aged 14 was 25 percent and for children aged 5-9, 11 percent (Robertson, 1987). Head injuries to children less than 4 years old in one emergency room declined 26 percent from before to after the child-restraint-use law in California; changes in less severe injuries were statistically insignificant (Agran, Dunkle, and Winn, 1987).

Motor vehicle occupant deaths of young children (per 100,000 population in that age group) declined about 30 percent from 1968 to 1979 (Baker et al., 1984) in association with motor vehicle safety standards and the 55 mile-per-hour speed limit. This trend should not have continued into the 1980s because the effects of those policies were fully realized by 1980. Child-restraint laws no doubt account for some of the reductions in child occupant deaths in the 1980s. One analyst attributes 153 fewer child deaths in 1985 to the laws (Partyka, 1989). The reductions were found despite numerous exemptions in state laws. An analysis of state laws requiring child-restraint use found that 39 percent of the children O-5 years old killed in the year preceding the law were not covered by the law because of age or other exemptions (Teret, Jones, Williams, and Wells, 1986). If the exemptions had not retarded restraint use, an estimated additional 98 children ((153/0.61)-153) would not have died in 1985.

It is not possible to estimate savings from eliminating the exceptions in child-restraint laws because data on the number of child seats that would have to be purchased and the cost of law enforcement are unknown. Many areas have child-seat loan programs that allow reuse of seats, but the extent of reduction in cost attributable to these programs is unknown.

The cost of the administration of laws has seldom been studied. The cost of police enforcement varies depending on whether police are reassigned from other duties that are more or less beneficial or whether the police force is expanded. Certain laws such as administrative license suspension for driving while intoxicated (DWI), mandatory jail sentences for DWI, and required use of safety belts have been found to have some effect on fatalities. Administrative license suspension for DWI expanded to the 75 percent of states without such a policy would save $1.7-$4.6 billion, less the cost of administration. Mandatory jail sentences

Table 28
Examples of Injury Control Countermeasures with Known Effectiveness: Data Needed for Savings Analysis

Intervention	Effect (% reduction)	Percent Unapplied*	Severity Distribution	cost of Injuries	Cost of Intervention
Pediatric counseling on infant falls (Kravitz, 1973)	41% of treated falls	Unknown	Unknown	Unknown	Unknown
Fenced swimming pools (Pearn et al., 1979)	65% child pool drownings	Unknown	Unknown	Unknown	Unknown
Alcohol taxes (Cook, 1981)	7% auto fatals per 10% increase in liquor price	Varies by state	Unknown	Unknown	Unknown
Breakawav bases for softball (Janda et al., *1988)*	95% sliding injuries	Unknown	see ref.	$1,223 per injury	$48 extra per base
Administrative license suspension for DWI (Zador et al., 1988)	5% of all fatals	75%	Estimated by ratio per death	$1.7-$4.6 billion	Unknown
First offense mandatory jail sentence for DWI Zador et al., 1988)	2% of all motor-vehicle fatals	76%	Estimated by ratio per death	$700-$1,857 million	Unknown
Belt use laws (Williams and Lund, 1988)	7% front occupant fatals	20%	Estimated by ratio per death	$342-$906 million	Unknown
Gun registration and waiting period (Medoff and Magaddino, 1983)	24% suicides	Unknown	Unknown	Unknown	Unknown
Repeal right-turn-on-red laws (Zador et al., 1982)	57% pedestrian injuries at such sites	Unknown	Unknown	Unknown	Unknown
Required smoke detectors in homes (McLoughlin et al., 1985)	25% fatal	Unknown	Unknown	Unknown	Unknown

Table 28 (Cont.)

Intervention	*Effect* (% reduction)	Percent Unapplied'	Severity Distribution	cost of Injuries	cost of Intervention
Window barriers in high-rise buildings (Bergner, 1982)	90%	Unknown	Unknown	Unknown	Need updated figures
Amber timing at intersections (Zador et al.,1984)	Potential 12-70% all such crashes	Optimally unknown	Derivable from NASS	Derivable	Unknown
Flashing lights at rural stop signs (Hagenauer et al, 1982)	80% fatal	Unknown	Unknown	Unknown	Unknown
Pedestrian-friendly vehicle front ends (Ashton, 1982)	30% fatal	Unknown	Derivable from NASS	Derivable	Unknown
Reflective tape on outline of large trucks (Burger et al., 1986)	18% night- time car into truck crashes	Unknown	Unknown	Unknown	Unknown
Breakaway utility poles near roads (McFarland et al., 1979)	30% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Need updated figures per pole
Remove u tilitv poles from roads (McFarland et al.,) 1979)	38% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Need updated figures per pole
Remove trees from roadsides (McFarland et al., 1979)	50% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Need updated figures per tree
Impact attenuators at fixed objects (McFarland et al., 1979)	50-75% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Varies by type
Breakaway signs (McFarland et al., 1979)	40-70% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Varies by type
Improve guardrail ends (McFarland et al., 1979)	55% fatal of such crashes	Unknown	Unknown	Unknown	Varies by type

Table 28 (Cont.)

Intervention	Effect (% reduction)	Percent Unapplied+	Severity Distribution	cost of Injuries	cost of Intervention
Transition guard-rail at bridge ends (McFarland et al., 1979)	55% fatal of such crashes	Unknown	Unknown	Unknown	Varies by type
Upgrade substandard guardrail McFarland et al., 1979)	15% fatal of such crashes	Unknown	Unknown	Unknown	Varies by type
Concrete median barrier McFarland et al., 1979)	85-90% fatal crossover head-on	Unknown	Derivable from NASS	Unknown	Need updated figures
Widen bridges (McFarland et al., 1979)	50% fatal of such crashes	Unknown	Unknown	Unknown	Varies by type
Improve curve delineation (McFarland et al., 1979)	**16%** fatal of such crashes	Unknown	Unknown	Unknown	Need updated figures
Channel left turns (McFarland et al., 1979)	42% fatal of such crashes	Unknown	Unknown	Unknown	Need updated figures
Lighting freeways (McFarland et al., 1979)	50% fatal of such crashes	Unknown	Derivable from NASS	Unknown	Need updated figures
Flashing lights and gates at rail-highway crossings (Pinnell et al., 1982)	60-80% fatal	Unknown	Unknown	Unknown	Unknown
Limited access to businesses on rural roads (Stover et al., 1982)	33% fatal at appropriate sites	Unknown	Unknown	Unknown	Unknown
One-way urban streets (Parsonson et al., 1982)	10-50% pedestrian injuries	Unknown	Unknown	**Unknown**	Unknown

* Percent of population for which interventions have not been implemented

for DWI in the states without it would save $342-$906 million, but the unknown cost of administration and keeping prisoners would substantially offset those savings. Mandatory belt use in the states without it would save $700-$1,858 million, less the cost of enforcement and administration.

The lack of data on administrative and enforcement costs, as well as arguments over the effectiveness of laws such as gun control laws, also impedes savings analysis. More than half the suicides and homicides in the United States are committed with firearms. Controlling for age, income, religion, region, and occupational status, laws that require a license or waiting period for purchase of a firearm are associated with a reduction in suicides of 3 per 100,000 population (Medoff and Magaddino, 1983).

Such laws have generally been found more effective than laws that prohibit carrying concealed weapons, presumably because they are more enforceable (Lester and Murrell, 1982). Another study estimated that if New Jersey's law had been applied in all states in the 1960s, some 4,200-6,400 fewer deaths would have occurred annually from suicide, homicide, and unintentional firearm injuries (Geisel, Roll, and Wettick, 1969). The New Jersey law included licensure of dealers and purchasers; delay between purchase and acquisition; maintenance of records of sales; restrictions on sales to felons, drug addicts, alcoholics, mentally ill persons, and minors; and restrictions on carrying handguns in motor vehicles or as concealed weapons. The results of that study have been questioned because the correlation was reduced when controls for region of the country were introduced in the analysis (Magaddino and Medoff, 1984).

Recent research compared assaults and homicides in Seattle and Vancouver, the latter with stricter rules regarding gun ownership. Gun ownership is not allowed for 'self-protection' in Vancouver but is allowed in Seattle. The two cities, 140 miles apart, have similar weather, unemployment, education, household income, and burglary and robbery rates. Although aggravated assaults and homicide rates, excluding those in which guns were involved, were similar in the two cities, the firearm assault rate in Seattle was 7.7 times that in Vancouver and the firearm homicide rate was 5.1 times higher (Sloan, Kellerman, Reay, et al., 1988).

Since the lack of uniformly strict state laws regarding gun licensure and waiting periods allows for interstate transportation of guns by unqualified owners from less to more strict states, it is likely that a uniform policy would have more effect than has thus far been demonstrated by comparing the experience of states with different laws.

Research on the effect of allowing drivers to turn right on red at signalized intersections indicates an overall 57 percent increase in pedestrian collisions in states where the law allowed right turns compared to states with no change in the law during the same period. Studies of all intersection crashes attribute only about 1 percent to right-turn-on-red (Hagenauer,Upchurch, Warren, and Rosenbaum, 1982), but the studies include dubious assumptions regarding the validity of police reports on the color of lights at the time of the crashes before the officer arrived. If the right-turn-on-red laws were repealed, the number of intersections where the signs would have to be changed and the cost of such changes is unknown.

Comparison of a county with a law requiring smoke detectors in homes to a county without that requirement suggests that the requirement is associated with a 25 percent reduction in deaths from housefires. About 67 percent of U.S. households had smoke detectors in 1982 (U.S. Fire Administration, 1983), but the extent of coverage of smoke-detector legislation is unknown.

Fatal falls of children crawling out windows of multistoried buildings were reduced 90 percent in New York City in association with programs promoting the use of window barriers and regulations requiring such barriers. The number of barriers needed in other cities is unknown.

Motor Vehicle Environments

The length of the yellow phase of traffic control lights among signalized intersections is associated with a substantial difference in crash rates, the degree depending on the length of the lights (Zabor, Stein, Shapiro, and Tarnoff, 1984). A review of other studies suggests less effect in before-after comparisons when lights are changed (Hagenauer et al., 1982). The lack of use of control groups of intersections without light changes does not allow estimation of changes in crash rates that would have occurred without the light changes. An all-red interval after a green in either direction at intersections has also been associated with reduced crash rates (Hagenauer et al., 1982). The distribution of the timing of yellow lights and the use of all-red phases is not known, nor is there a good estimate of the range of injury severity affected.

Use of flashing lights at approaches to stop signs at rural intersections is associated with substantially reduced crash rates. One study found a 51 percent reduction in injuries and an 80 percent reduction in deaths at installation sites (Hagenauer et al., 1982). Better controlled research and a census of relevant sites are needed to assess the savings potential of the use of warning flashers.

Comparison of injuries to pedestrians struck by the frontends of vehicles in England suggests that a 30 percent reduction in pedestrian fatalities could be achieved if all vehicles were designed to reduce the energy exchanges from points, edges, and characteristics related to the kinematics of the event. Since some of these changes would result in less use of materials, such as elimination of sharp points on the front corners of several large American cars, there could possibly be a lower cost of at least some vehicles as well as savings in injury costs. The extent of all the changes needed in U.S. vehicles has apparently not been studied in sufficient detail for savings analysis.

Comparison of large trucks with reflective tape defining the outline of the trucks and trucks without the tape indicates a 15 percent reduction of car-into-truck crashes associated with reflectorization. The extent of use of this approach is unknown, but trucks with striping are rarely seen on the roads.

Fatal crashes that occur when vehicles cross into the paths of oncoming vehicles are reduced 85-90 percent by concrete barriers that are flared at the bottom to guide an errant vehicle back into its lane. While the cost of such installations per mile can be obtained, the number of miles of road at high-risk sites is unknown.

Crash rates related to bridge width are a function of both bridge width and the width of the approaching road (Bissell, Pilkington, Mason, and Woods, 1982). Widening of bridges is associated with an average 50 percent reduction in fatal crashes related to bridge width. Modifications of the road approach, such as diagonal shoulder markings, continuous guardrail tapered before the bridge structure and post-mounted delineators behind the guardrail, have also been demonstrated to reduce bridge crashes substantially. The number of bridges that could be widened or approach roads modified to achieve the maximum reduction in injury is unknown.

As noted previously, motor vehicle crashes occur disproportionately on or near curves. Better delineation of curves (edge and center stripes, roadside and center reflectors, and the like) is associated with about 16 percent reduction in fatal crashes on modified roads. The miles of road curvature lacking such delineation is unknown. Curved road sections with low or absent cross slopes are particularly hazardous when wet. At one such section on the Washington, DC beltway, Congressional staff on rainy days filmed cars spinning and some that had spun off the road, going over embankments or striking bridge abutments (Kelley, 1972). One study found an average 25 percent difference in crashes per mile between sites that had no cross slope and a 0.025 ft. downward slope per foot of road in an area with an average rainfall of 60 inches per year (Dart and Mann, 1970). The extent of the problem nationally and the injury reduction that would be realized from modification of cross slopes is unknown.

Pavement grooving has also been found to be effective in reducing crashes on wet roads, but the estimates vary widely among studies -- 27 percent reduction in Louisiana, 69 percent in California, and 62 percent in Baltimore. One study in Ohio indicated increased crashes on grooved sections in dry weather, but the other studies did not find a significant effect on dry-pavement crashes (reviewed in Gallaway, Benson, Mounce, Bissell, and Rosenbaum, 1982). The injury severity distributions in these crashes and extent of surfaces that would produce benefits from grooving are unknown.

At intersections, lanes that channel left-turning vehicles out of the path of through traffic are associated with a 42 percent reduction in fatal crashes compared to intersections without this feature. Channeling is more effective at unsignalized intersections (54% injury reduction) than at signalized intersections (36% injury reduction), (Hagenauer et al., 1982). Identification of the numbers of high-risk intersections that would produce a savings from channeling has apparently not been done.

About 50 percent fewer fatal crashes occur on lighted sections of urban freeways compared to unlighted sections. Studies of lighting on several major routes indicate that lighting less than 0.4 horizontal foot candles is ineffective at best and may increase crashes (Schwab, Walton, Mounce, and Rosenbaum, 1982). Also, the placement of light poles near the road may increase the crash rate and, if they do not break away on impact, the severity.

Intersection crash rates at night are substantially lower at lighted compared to nonlighted intersections, 25 to 86 percent lower depending on such elements as type of intersection, type of crash, and number of lanes (Hagenauer et al., 1982), but data on relative severity and numbers of intersections involved by type are inadequate for estimation of savings.

Studies of sight distance impaired by hedges, fences, and the like at intersections indicate substantial reduction of crash rates associated with greater sight distance (Hagenauer et al., 1982). However, the relative severity of associated injuries and the extent of the problem have not been adequately studied for savings estimates.

Crashes of motor vehicles and trains at intersections of roadways and train tracks are often very severe. The effectiveness of warning devices such as flashing lights and gates has been estimated at 64 to 80 percent reduction in severe and fatal injuries in such crashes (Pinnell, Mason, Berg, Coleman, and Rosenbaum, 1982). Separation of motor vehicle and rail traffic by overpasses is obviously even more effective. In 1973, the Highway Safety Act authorized federal assistance for improvements at railroad crossings. About $1.2 billion was expended to eliminate or modify 5,600 railroad crossings in the ensuing decade. The numbers of motor vehicle fatalities at such crossings declined from 1,128 in 1974 to 542 in 1984 although exposure increased 4 percent (Dempsey, 1985). If the deaths had continued at the 1974 rate, about 2,500 more people would have died and nonfatal injuries of unspecified severity would have declined 28 percent. The reduced deaths alone resulted in a savings of about $1 billion in human capital terms or approximately $5 billion by willingness-to-pay estimates, the latter several times the expenditure for the improvements. Since the installations will continue to produce savings, the total return will be larger.

Crashes per mile on rural highways are strongly correlated to number of business accesses per mile. Often in a string of adjacent businesses, each has its own parking lot and entrance. The parking lots could be joined and the in-and-out traffic channeled to a single entrance. The data suggest that an average 33 percent reduction of fatalities could be achieved on roads with no access control if they were changed to partial access control (Stover, Tignor, and Rosenbaum, 1982). The number of road sections that would produce benefits from partially limited access is unknown.

In urban areas, changing traffic flow on a street from two-way to one-way traffic frequently results in reduced crashes and pedestrian injuries, although the variation is wide, 10 to 50 percent. Efficiency of traffic flow is also usually a benefit (Parsonson, Nehmad, and Rosenbaum, 1982). To specify the savings involved, more research is needed on the types of streets that would produce benefits, their numbers, and the distribution of crash severities.

In 1985, almost 12,000 motor vehicle fatalities occurred in collisions with fixed objects near roadsides -- trees or shrubbery (2,967), utility poles or signs (2,221), guardrails (1,129), and other objects (5,477). Research indicates that 50 to 75 percent of these fatalities could be prevented by removal of trees from roadsides, impact attenuators, breakaway poles and signs, and improved guardrails. The current cost of such modifications per modification can be obtained, but the number of sites that need modifying is unknown.

Targeting Interventions

As noted above, the cost of applying many interventions is dependent on the extent to which they are targeted to high-risk populations or sites. For example, research comparing sites of fatal crashes into fixed objects with sites one mile in the direction from which the vehicles traveled indicates the high-risk sites can be substantially identified by road characteristics. Twenty-five percent of the crash sites were within 500 feet of curves greater than 6 degrees with downhill grades greater than 2 percent. Only 8 percent of the comparison sites had such characteristics. There was no difference in number of objects along the road at the fatal and comparison sites (Wright and Robertson, 1976). Use of such epidemiologic studies to set priorities would decrease the cost of many interventions relative to the cost of associated injuries.

An example of one such successfully targeted intervention occurred on Queens Boulevard in New York City. Spot maps of pedestrian severe and fatal injuries during 1980-84 revealed clusters on this widest street in the city. Eighty-five percent of the persons injured were aged 65 and older suggesting that interventions related to walking speed and vision, as well as speed control and education, might be effective (Retting, 1988). In 1985, several countermeasures were introduced at a total cost of about $150,000: 1) timing of lights was changed to increase pedestrian crossing time; 2) pedestrian signals were placed on median islands; 3) roadway markings were increased to identify pedestrian walkways and traffic flow; 4) size of speed limit signs was increased and speed enforcement increased; and 5) presentations on pedestrian safety were given at senior citizen centers. The deaths and severe injuries in the targeted area were 3 per year in the two years after these measures were introduced compared to 8 per year in the five years before.

Feasibility

Effectiveness and savings analysis ignores feasibility of implementation because of ideological factors and concentrated interests that may oppose certain interventions. Policies such as government subsidization of bicycle helmet purchases, while acceptable in Australia, may be difficult to implement in the U.S. Although the majority of motorcyclists are in favor of helmet use laws, a vocal minority have been successful in gaining repeal in many states (Baker, 1980). Seemingly overwhelming ideological opposition or lobbying power is not always as solid as it appears, however. No one familiar with Tennessee politics would have expected that state to be the first to enact a child-restraint use law, but it did, and other states followed. The gun lobby spent $6 million in an attempt to defeat Maryland's new gun control legislation but was overwhelmingly defeated in a referendum in the 1988 election.

The incremental approach discussed here also neglects the question of the circumstances under which the injurious consequences of certain products are so severe relative to whatever uses they have that they should be banned. In the 1960s, about 700 people per year in the U.S. died on motorcycles. As a result of massive advertising of motorcycles aimed at a broad spectrum of the population (Sakiya, 1982), sales soared and motorcycle registrations increased from about 500,000 in the 1960s to 5.6 million by 1984. Deaths on motorcycles rose from 700 to 4,600 per year. In the 1980s, racing motorcycles capable of speeds of 160 miles per hour were introduced for street use. These racing motorcycles have death rates about twice those of other motorcycles (Kraus, Zador, Arzemanian, Anderson, and Harrington, 1988).

A marketing effort similar to that for motorcycles, but directed to children as well, led to a large increase in sales of so-called 'all-terrain vehicles' (ATVs) and an accompanying increase in deaths. In this case, however, the government acted while the deaths were in the hundreds, rather than the thousands, per year. The industry has agreed to stop marketing 3-wheeled ATVs, but the Consumer Product Safety

Commission allowed continued marketing of 4-wheeled ATVs in a compromise to avoid extensive litigation, although 4-wheeled ATVs may be as unstable as 3-wheelers (Kitzes, 1989). The government has refused to act on numerous other product-related hazards (Berger and Rivara, 1980; Christoffel and Christoffel, 1989; Robertson, 1989).

Conclusion

There is some uncertainty in each of the estimates of potential for injury reduction because of variation in sampling error and the lack, in some cases, of good experimental design. There is, however, no doubt that a substantial proportion of severe injuries could be reduced by a greater application of current knowledge. The potential savings, net of the cost of injury control programs, is in the billions of dollars for the interventions for which data are available. Usually, savings estimates are far more sensitive to differences caused by using the human capital or the willingness-to-pay method than to variation in estimates of effectiveness of a given intervention. For example, there is nearly a four-fold difference in savings from air bags estimated by the human capital method compared to the willingness-to-pay method. There is, however, no such variation in estimated effectiveness of air bags.

Savings in the billions of dollars were found for air bags ($5-$19 billion), a minimum licensing age of 17 ($1.4-$4.3 billion), and the elimination of driver education from the public schools ($0.8-$2.2 billion). Tens of millions would be saved by reduced cigarette paper porosity ($187-$1,100 million), high seat backs in cars ($14 million), motorcycle helmet laws in states without them ($97-$1,200 million), bicycle helmet use promotion ($183-$284 million), and child-pedestrian programs ($58-$180 million). Estimated by the willingness-to-pay method, the savings from automatic headlamps on cars and light trucks ($534 million) and increased side crash protection for cars ($1.5 billion) are large. Because of the exclusion of the cost of property damage, the estimated savings for eliminating high school driver education, increased licensing age, reduced cigarette ignition, and automatic headlamps are substantially understated.

As noted in the discussion above of the estimates for driver education and licensing age, the savings from some programs or policies, if implemented, would reduce the savings from others. Several of the programs and policies mentioned are independent of one another, but there is overlap in those related to injuries in or by motor vehicles. For example, air bags would reduce some of the injuries that would also be reduced by changes to the road environment, and these changes would contribute to a part of the reduction in motorcycle and bicycle injuries, which would also be reduced by increased helmet use.

Although complete information needed to calculate the precise savings that would result from implementing numerous approaches is missing, the cost of preventable injuries is so large that implementation would have to be enormously expensive to contraindicate action. Cost could be reduced substantially by collection and use of better data on the clustering of injuries geographically in some cases and in particular populations in others. Better data on the extent of current implementation and cost of implementation would contribute to more rational choices among programs and policies.

Chapter 6

Long-Term Impact of Injury on Individuals, Families, and Society

Personal Narratives and Policy Implications

Every injury resulting in severe disability causes profound personal, familial, and social impacts over the long term. An injury episode is not only physical and physiological, but is a deeply personal event occurring in an extended interpersonal and social context. What happens to severely injured individuals in the United States is a result not only of the physical trauma itself and the quality and extent of the medical care that follows, but also of the long-term support available from a variety of sources: family, friends, community groups, health care and social service delivery systems, and legal, insurance, and political institutions. The ability of severely injured people to attain maximum physical recovery, to survive financially, and to reorganize their lives within new limitations is dependent on a society with laws and policies that constrain or enable secure, productive lives regardless of inhibited functional status.

The case studies below illustrate what happens to people with severe disabilities in the various contexts that impinge directly upon their well-being in the months and years following an injury. Together, these case studies tell a story of the struggle to acquire the personal, therapeutic, legal, and financial aid that enables injured persons to survive, have basic needs met, and create for themselves lives that are meaningful in terms of work, love, mutual support, recreation, and personal growth. A major disability resulting from injury shatters an individual’s world. Basic routines and activities of daily living can no longer be taken for granted. One’s place and role in family, community, and society are no longer the same. One never returns to previous conceptions of ‘normal.’ Perhaps most importantly, following an injury, one’s entitlement to society’s resources such as jobs, housing, education, and transportation is no longer automatic. Severely injured people have a ‘betwixt and between’ or undefined social status regarding their roles as productive participants in community life and as autonomous, decision-making beings. “They are neither ill nor well, neither socially alive and active nor socially expunged and removed” (Murphy, Scheer, Murphy, and Mack, 1988). A sudden disability renders an individual’s access to medical and social services, work, and housing questionable. A negotiation process over access begins immediately following the injury and continues sometimes for years.

The most comprehensive finding of the present study is that all participants needed to negotiate with health care, legal, and insurance institutions in order to secure a place for themselves in society following an injury. Access to long-term rehabilitation, psychological support, appropriate attendant services, housing, medication, equipment, and employment opportunities all had to be negotiated, or even fought for, within the regulations and policies of particular agencies and institutions. Thus, documenting the personal, noneconomic costs resulting from an individual's or family member's injury involves discussion of the social institutions in which their lives are embedded, the solutions those institutions are able to provide, and the problems they sometimes create.

Methods and Subjects

The following pages describe what happened to ten individuals and some of their family members over a period of two to eighteen years following a severe injury. Interviewees were selected from health care and social service professional referrals. Only mentally alert, expressive, articulate individuals were selected as subjects for this study in order to gather detailed information on the full range of the injury's ramifications. Thus, the ability to express oneself was the first criteria for subjects chosen. Second, subjects chosen had mechanisms of injury typical of those occurring in the U.S., and common residual disabilities as well. Third, the personal stories of the ten individuals, though unique and idiosyncratic, are similar to thousands of other injury and disability stories. Thus, the case studies were carefully chosen to be widely representative of injury and its aftermath. Moreover, study participants were ordinary citizens. None were wealthy or famous. All were forced to make difficult choices under tragic circumstances. Their stories illustrate the financial, social, and institutional constraints that influence the decisions and give shape to the opportunities of injured persons. The stories are a testament to the strength of the human spirit under great adversity.

The case studies illustrate the following injury-causing episodes: automobile crash, motorcycle crash, near drowning, diving into shallow water, contact sport, brutal beating, fall following an illness, fall in the workplace, and crush following malfunctioning workplace equipment. The studies represent the following residual disabilities: quadriplegia, ventilator-dependent quadriplegia, both mild and severe brain damage, severe central nervous system damage, facial disfigurement, amputated and deformed fingers, functionless hand and arm, and general weakness and inability to walk. The names used are pseudonyms and identifying information has been eliminated in order to preserve anonymity. The case studies portray events and responses from the point of view of the injured person or a family member who was the major caregiver of the injured person. The studies are entirely subjective (see Appendix B for a full description of methods).

Data were collected from five injury survivors, four parents of survivors, one spouse, and one sibling. The small study group does not adequately represent the ethnic diversity of the U.S. population or of the greater San Francisco Bay Area, the location of all the interviews. The study group, however, represents a range of economic, occupational, and educational backgrounds. The California study group possibly had more services available than in other places in the country.

‘Invisible’ Survivors

There are thousands of severely disabled individuals in the San Francisco Bay Area. Yet finding injury survivors or family members who fulfilled the study eligibility criteria and who would share their experiences with an empathetic researcher proved to be exceedingly difficult. Many scholars have noted how the disenfranchised and alienated are ‘invisible’ members of American society (e.g., Harrington, 1962; Sheehan, 1976). In spite of the growing lobbying strength and visibility of the disability rights movement over the past decade, the disabled, as individuals, have muted voices. People with disabilities seldom seek publicity. Potential subjects and their families were difficult to locate, even with the help of informed, energetic professional contacts. Members of ethnic minorities with disabilities and their families were even harder to find and thus are under-represented. Appropriate subjects who had suffered from firearm injuries were not located. Most injured people known to medical or allied health personnel had moved numerous times since their acute care or rehabilitation hospitalizations, and providers did not know where to find them. The fact that locating expressive individuals (especially ethnic minorities) with disabilities was so challenging is an important finding in itself. If representatives of the disabled population cannot easily be found to share their personal experiences, it will continue to be difficult for their collective needs to be articulated to policymakers at the local, state, and federal levels.

The goal of presenting a small number of case studies is to illustrate how survivors and their families interpreted what happened to them in the days, months, and years following a severely disabling injury. The subjects presented experiences, events, and concerns that have emerged as central to their lives two to eighteen years after the injury occurred. The aim is to present a range of injuries, disabilities, family dynamics, economic situations, and concerns about health, work, productivity, and dependence. Health care, social service, government, and insurance industry professionals would, of course, have different stories to tell.

Defining Disability

Criteria used to define disability vary widely in the literature. Krause (1972) distinguishes among three kinds of disability: biopsychosocial, social role, and legal disability. Social role disability, the definition employed in this chapter, refers to health-related limitations in performing the social roles expected of an individual, such as going to school, performing work at a job, or doing housework (Nagi, 1979; Rice and LaPlante, 1988). Similarly, the World Health Organization defines disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or in the range, considered normal" (WHO, 1984).

Biopsychosocial definitions are made by physicians and others qualified to judge physical and mental functioning by generally accepted standards. The legal definition of disability is used to determine an individual's entitlement to benefits from government programs, especially Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The definition for SSDI is relatively stringent: "Persons awarded benefits must have been judged to be unable to engage in any substantial gainful activity in the national economy, not merely in their own usual occupation, by reason of a physical or mental impairment. . . . The impairment is medically determined and must be expected to last a year or to result in death' (U.S. SSA, 1987b). The legal definition of disability is much more restrictive than the social role definition.

Ability and Desire to Work

Regulations, Access, Disincentives

In a recent book about the personal, cultural, and social dimensions of disability, Robert Murphy states: "Most disabled people would prefer to work, even at low-paying jobs, rather than live on the Social Security rolls, but if their earned income exceeds a very low limit, they lose both their pension and their government health insurance. This is a critical matter, as their medical expenses usually are much higher than those of ordinary people. Even if they are accepted by an employer's private plan, these generally do not pay for attendants and certain costly equipment. In this classic bind, many disabled people cannot afford to be employed! . . . The system itself promotes dependency" (Murphy, 1987, pp. 159-160).

Social Security Disability Insurance (SSDI) provides benefits to eligible disabled persons (and their dependents) who have worked under and contributed to the Social Security system (2 million recipients in 1986). The amount of the benefit is directly related to the amount of time worked and money paid into the system. The maximum benefit available from SSDI in 1988 was $800 a month. Supplemental Security Income (SSI) is intended for eligible disabled persons who fall below a certain income/assets level (3.9 million recipients in 1986). The monthly SSI benefit in 1988 was $354. Many states supplement the SSI benefit; the California supplement in 1988 was $221 a month. In order to be determined disabled under Social Security law, individuals must have a physical or mental impairment expected to last for at least a year, which prevents them from doing any substantial gainful work. Partial disabilities, which are recognized in many benefit programs, are not sufficient to qualify one for SSDI or SSI. Social Security's medical requirements are strict and only about one-fourth of the initial claims received each year are allowed. Persons considered severely disabled may be denied benefits if they are capable of substantial gainful work.

Since 1972, Medicare coverage has been extended to disabled persons. Hospital insurance protection and optional supplementary medical insurance is provided to disabled individuals who have been entitled to SSDI benefits for at least 24 months. Most SSI recipients are also covered by Medicaid. In fiscal year 1985, nearly 3 million (2,936,000) individuals with permanent and total disabilities received Medicaid benefits (U.S. SSA, 1987a). The following case study illustrates the ramifications of the employment bind in which many people with disabilities find themselves.

Alan Bensen -- Eighteen Years of Quadriplegia

Approximately 200,000 people in this country live with paralysis as a result of spinal cord injuries. Each year it is estimated that there are approximately 2,500 new cases of paraplegia and 1,050 new cases of quadriplegia. About 56 percent of the injuries resulting in these disabilities are caused by motor vehicle crashes, 20 percent by falls, 12 percent by firearms, 7 percent by sports and recreational activities, and 6 percent by other sources (DeVivo, Fine, Maetz, and Stores, 1980 and extrapolated from Kraus, Franti, Riggins, Richards, and Borhani, 1975).

In 1969, at the age of 18, Alan Bensen dove into a lake and broke his neck when he hit the bottom. He was instantly and permanently paralyzed below his collarbone, but maintained arm function. His friends pulled him out of the water and got him to a hospital. He spent a few weeks in intensive care at an acute care hospital and then was transferred to a rehabilitation hospital. He was hospitalized a total of nine months. Mr. Bensen had graduated from high school the year before his injury and had spent the preceding year working in a factory, saving money, and deciding what to do next. Both of his parents were working in factories at the time of his injury. From the hospital, Mr. Bensen moved home with his parents. They worked different shifts and one of them was always at home to care for their son. Mr. Bensen lived at home for about a year, learning to function. His parents were his primary caregivers. They initiated a lawsuit against the owner of the lake property shortly after the injury. They lost the suit but owed no legal fees. The case ended in 1972.

For seven years following the injury, Mr. Bensen had many hospitalizations and surgeries for various injury- and quadriplegia-related medical problems. He recalled a period when he was hospitalized every few months. His problems were those common to quadriplegics – urinary tract infections and upper respiratory infections, including pneumonia. In 1971, he had an ileal diversion, the removal of his bladder. He also had surgery three times on his right arm and hand to allow the thumb to function so he could write and hold objects securely. Both types of surgery were elective. All his medical bills -- acute care, rehabilitation, outpatient, successive surgeries -- and his related costs -- attendant care, a wheelchair-accessible van, and medical supplies – were covered by medical insurance. His initial acute care and rehabilitation costs were covered by his mother’s employee insurance policy. By the time she retired, Medicare was covering Mr. Bensen’s total health care costs. Medicare payments began for Mr. Bensen in 1973.

Education and Job Discrimination

Mr. Bensen attended the state university as a full-time student from 1973 to 1977, graduating with a B.A. degree. He lived in an apartment with an attendant and a roommate during most of his undergraduate education. Friends drove him to and from school and transferred him in and out of the car. While he was a student, he spent three to five hours a week at the university gym doing rehabilitation therapies and learning how to do more things independently. One of the therapists at the university taught him to drive. He began with hand controls in a borrowed car. Then he bought his own car and had hand controls installed. This was of limited value, he recalled, because he could not get himself in and out of the car and could not go anywhere unless transfers were arranged at both ends. A free van with a lift acquired from the Midwest state vocational rehabilitation department during his senior year enabled him to become independently mobile. He was fortunate that the department had a surplus in the budget and was eager to spend the extra money.

Mr. Bensen stayed out of school for the next three years while he considered options and applied to law schools. He drove in his van, with a friend, around the country to look at a few law schools. He eventually decided to come home and apply to the state university law school, which accepted him. He began there in 1980 and finished in 1983. He applied for many more jobs than his peers and was aware of discrimination because he was in a wheelchair (see Murphy, 1987 and Vash, 1981 for a discussion of job discrimination experienced by the disabled). He finally got a job in a small town (pop. 750) in another state. He went there for seven months in 1984. He recalls that there was absolutely nothing to do there aside from his work, and in addition, no public buildings were accessible to him. He decided to move to the San Francisco area and live with a friend.

Mr. Bensen contacted all the county offices around San Francisco to learn about subsidized housing for the disabled. He moved into the suburban apartment in which the interview was conducted early in 1985. He studied for the California bar exam and passed on the first attempt, in the summer of 1985. Again, he spent a long time looking for a job. First, he had a half-time job for a few months. Then he got the public sector law job he held at the time of the interview. For two years he worked at that job full-time.

Increasing Medical Vulnerability

Mr. Bensen said that he had recently cut his work schedule back to four days a week, taking Wednesdays off because he was getting physically sick working ten hours a day, five days in a row. He simply did not have the physical stamina to continue at that pace. At age 38, Mr. Bensen had recently become aware of his increasing vulnerability to a variety of health problems. The scoliosis in his lower back was getting worse, and he felt he would eventually need to have his lower spine fused. He would probably go back to the Midwest for the surgery because he does not have a doctor in California and he knows and trusts the doctors back home.

Attendant Services That Work

Mr. Bensen's SSDI payments began in 1970. Through his SSI eligibility, Mr. Bensen simultaneously became eligible for both In-Home Support Services (attendant services) and Medical (California Medicaid). The In-Home Support Services Program pays for his morning and evening attendants, 170 hours a month, or five to six hours a day. He hires his own attendants by running ads in local papers and interviewing applicants. Mr. Bensen has lived with a woman friend, on and off, for many years. They met in his home town. She works as a teacher and also as his paid attendant during the evenings and on the weekends. The attendants help him get up, out of bed, dressed, and assist him with a range of motion exercises. The personal assistance service system works efficiently for him.

Classic Bind: Employment or Benefits

Mr. Bensen's SSDI payments started at $135 a month and had risen to $651 a month when he was dropped from the program in April 1987. Current federal regulations stipulate that one can be employed for only fifteen months -- the Trial Work Period - while covered by SSDI, at which point the payments are terminated. Mr. Bensen was appealing this ruling to the Social Security Administration at the time of the interview. He said appeals are sometimes resolved at that level. If not, he will consider appealing to the federal courts.

Catch 22: Disabled or Employable

Federal regulations have created a dilemma for Mr. Bensen. At the time of the interview, he was receiving $675 a month in social security payments due to be terminated in two months. He said: "They don't consider me disabled any longer because I have been working for more than 15 months." The rules place him in a bind and force him to make a major decision. If he continues to work, the social security payments will stop, and he will have to keep working because it is almost impossible to re-start the payments. He said, "Most people worry about getting on the system. You don't hear too much about how they try to kick you off of it." Mr. Bensen was extremely anxious about this dilemma, noting again that he did not have a lot of physical stamina and was always vulnerable to medical problems. Working full-time was too hard for him. Yet, without social security payments, he would need to work full-time to survive financially. The anxiety and fear expressed by Mr. Bensen are pervasive among persons with severe disabilities.

System Promotes Dependence and Poverty

Federal regulations stipulate that a disabled individual can continue to receive social security benefits only if earning less than $300 a month. At the time of the interview, Mr. Bensen was trying to assess whether to work fewer hours at his job and pay for all his attendant care, van expenses, and other health-related costs out of pocket, so that he could deduct them, in order to pull his net earnings to just below the $300 a month ceiling. If Mr. Bensen decides to continue working full-time, thus losing his social security benefits, he will also lose his Medicare/Medical benefits because his income and assets are approaching those ceilings as well. He was not sure when those benefits would terminate, but he knew it was within the year. Medicare and Medical pay all his doctor bills and cover all his medical supplies. He could survive without those benefits only if his income were to increase substantially. He is caught in a bind created by government regulations. He wants to work as much as he is able, yet doing so may jeopardize both his financial and medical security.

Health care benefits and economic status are linked by federal regulations. In order to be eligible for Medicare benefits, a disabled individual under 65 must be receiving SSI or SSDI. And to qualify for Medicaid, one must be indigent (Murphy, 1987). Moreover, De Jong and Wenker (1983) frame the broader problem that a persistent feature of American publicly subsidized health and social service benefits is that they are inexorably and traditionally tied to an individual's earned income. These facts wreak havoc on a person's desire and ability to be a part of the workforce, to contribute to society, and to garner self-esteem in the economic marketplace. Mr. Bensen is a vital member of society who is being jeopardized by his ability to earn a living.

Olivia Evans -- Loss of a Hand, Loss of Free Choice

Mrs. Evans had been employed as a housekeeper at a community hospital for thirteen years when she was injured on the job. One evening in 1984, as she was routinely preparing to open the door to the laundry chute in the basement of the hospital, the latch became jammed. As she struggled with the door, she caught her right thumb in the latch and could not release it. It took three men to get her hand out. Later she learned there had been three tons of pressure on the door, and subsequently on her hand. She was in excruciating pain and was taken immediately to the hospital emergency room. There were multiple fractures in her thumb. She was treated and released. Ten days later she had a hematoma in her forearm and was still in severe pain. A month later (December 1984), though still in pain, she returned to work. In April 1985, her orthopedist recommended that she stop working because she had developed many more hand problems: swelling, greatly reduced strength (she could not hold a coffee cup), and much more pain. She finally quit her job. In May 1985, Mrs. Evans had hand surgery to release some of the tendons in an attempt to reduce the pain and swelling. She wore a cast for six weeks. When it was removed, her hand was not healed. Moreover, pains were shooting up through her arm and into her neck and head. Her doctor sent her to a hand rehabilitation therapist and she received hand therapy for two years.

By the end of 1985, Mrs. Evans had developed other symptoms that were a direct result of the injury. She could not move her right elbow, shoulder, or neck, lacked range of motion in the right arm, and had severe pain all through her right side. She began wearing splints at night to restore circulation to the right arm and reduce the numbness. She said that the left hand, due to overcompensation, had developed problems in the seven months before the interview. As a result, she was wearing splints on both hands at night, which she reported were extremely uncomfortable and prevented her from sleeping well. The hospital that had employed Mrs. Evans paid for all of her care: the emergency room surgery, subsequent doctor bills, subsequent surgery, and all hand therapy. They also paid her workers' compensation, 75 percent of her regular wages, from the time she stopped working until January 1987.

Discrimination Against People in Pain

Following the surgery, when Mrs. Evans was still complaining of severe pain, her surgeon said to her, "There is nothing wrong with your hand, it's all in your head. I want you to see a psychiatrist." She was humiliated and extremely angry that the physician thought she was imagining pain. She nevertheless went to a psychiatrist, who reassured her that the problem was in her hand, not her head. The hand therapists were familiar with the post-injury syndrome she suffered and they confirmed it as a physical, not a mental, problem. She resented the doctor's attitude so much that she decided to see a lawyer who brought a suit against the company that provided the laundry chutes to the hospital. She said her anger at her orthopedic surgeon pushed her to take legal action. The lawyer discovered that four people had previously been injured by the chute door. The lawsuit was still in progress at the time the interview was conducted. Mrs. Evans had no idea what the settlement might be. If she wins, she will receive 66 percent of the settlement.

Private Disability Plans Exist for Profit, Not for People

In 1986, the insurance carrier determined through its vocational rehabilitation service that Mrs. Evans could return to work. Officials informed her that she would have to switch occupations since she could no longer perform heavy work. She had been a seamstress in the 1960s, but she could not do the fine needle work anymore because of her injury. The insurance carrier expected her to find work related to sewing and expected her to look for a job by going to six potential places of employment a day until she found a job. After she had searched for a job for four weeks, the carrier found her a job as a bridal consultant at a boutique, designing, not sewing, the clothing.

As a hospital housekeeper, Mrs. Evans had earned $10.25 an hour with full health care and retirement benefits. She lived two miles from her work and drove there in about five minutes. The bridal consulting job began in January 1987 with a 45-minute commute, $7.00 an hour, and no benefits. At the time of the interview (May 1988), she had received a $1.00 an hour raise.

Suffering of Children

Mrs. Evans's husband died more than 10 years before the injury. She said, "The loss of my hand was in some ways worse than the loss of my husband. It was like another death in the family." At the time of the injury, her children were aged 10 and 18. She reported that the injury brought about definite, negative changes in the family. The children became depressed because they were not accustomed to seeing their mother helpless and unable to function. They needed to help dress and bathe her. "All the housework fell on them. They had to open bottles, peel potatoes, everything," Mrs. Evans said. "The children were sort of confined to school, home, and school again. We didn't have money for anything, not even the movies." She felt her children suffered through her injury even more than she did and said, "I feel I robbed my children of three years. They had to do for me, rather than me doing for them." She said she also went through her life savings following the injury. She borrowed $20,000 from a private party to cover her bills. At the time of the interview she was struggling to pay off that loan.

Private disability insurance is designed to get people through the system as quickly and efficiently as possible. In forcing individuals to quickly accept jobs, the industry does not consider the pain and suffering of the injured person, nor the appropriateness and wage level of employment secured. This policy undermines personal autonomy and self -respect.

Especially Vulnerable

Alone, Poor, and Unable to Work

The 1980 census revealed that 12,320,000 citizens between the ages of 16 and 64 had impairments that limited or prevented them from being gainfully employed. This was 8.5 percent of the total labor force. The median income of the disabled population was about 62 percent that of the nondisabled population in 1980. Correspondingly, one out of ten able-bodied people lived below the poverty line in 1980, and one in four people with disabilities were in the poverty group. This difference is due mainly to the fact that 58.2 percent of disabled men and 76.5 percent of disabled women are completely out of the labor force and must depend on public assistance for economic survival (Bowe 1983; Murphy 1987). The following case study shows how Mrs. Goode became a statistic in this group.

Bernice Goode -- Problems of a Hidden Disability

Each year, more than 75,000 people in the United States sustain brain injuries that result in permanent disability (Kraus et al., 1984; Kraus, 1985b). What happens to a brain-injured person who cannot work and who is not permanently cared for by a family member? Because of her injury, Mrs. Goode was unable to work. Yet, after many years in the labor force, she was denied social security benefits when officials could not adequately define the disability of this woman who spoke articulately and was not physically impaired. She nearly became homeless and destitute as a result of falling through the cracks in the system. A resourceful and compassionate rehabilitation counselor came to her rescue by creatively ‘packaging’ Mrs. Goode’s organic impairment so she could receive benefits from the Social Security Administration. Only then was Mrs. Goode able to live alone and begin to participate in community life.

In 1984, Mrs. Goode, at the age of 45, was severely beaten by a male acquaintance. She was at home, asleep. Her adult daughter was visiting from out of town. When the man arrived at about 2:00 a.m., Mrs. Goode’s daughter let him in the house and began talking with him. Mrs. Goode arose from bed and joined them in the kitchen. She reported that the man was on drugs and became violent. In a split second, Mrs. Goode decided to draw the man’s attention to herself to keep him from attacking her daughter. She went outside the apartment door, where he followed and beat and kicked her until she was unconscious. Her face was lacerated and her left arm was badly hurt. She does not remember being taken by ambulance to the nearest hospital. Mrs. Goode had been working as a Licensed Vocational Nurse for 14 years at one hospital. She enjoyed her job and felt worthwhile and productive in her caretaking role. She was earning $8 an hour at the time of the injury.

Mrs. Goode was in a coma for about a week in the hospital intensive care unit. She was hospitalized for two and a half weeks and discharged with mild brain damage and a severely bruised left arm and hand. She returned home and her daughter stayed with her for another month. Mrs. Goode recalled that she could not function on her own during that period. She could not use her left hand and arm at all. She experienced memory loss and severe vertigo -- nausea and dizziness when standing up or moving rapidly or spontaneously -- which she continued to suffer from at the time of the interview, four years later. When her daughter left, Mrs. Goode’s sister invited her to live at the sister’s home, realizing that Mrs. Goode could not be left alone. Friends helped her pack her belongings, put some possessions in storage, and make the 500-mile move to her sister's apartment. Mrs. Goode lived with the sister for one year, until the landlord told them that the lease specified one tenant only and that Mrs. Goode would have to leave.

For the first three months of her stay at her sister's home, Mrs. Goode took the bus three times a week to the Veterans Administration Hospital for physical therapy on her left arm. She received outpatient therapy for three months -- heat therapy and range-of-motion exercises. When she was discharged, her arm and hand were functional again. Her second husband was retired from the military, so she received the treatments as a dependent, free of charge. She was not divorced, but had not seen this husband since 1982 and did not know where he was living.

Not Sick Enough for Benefits

Mrs. Goode received disability insurance payments from her job for one year after the injury. When the disability insurance was terminated, which was at the same time she was forced to leave her sister's home, she applied for Social Security benefits. She was denied a claim. Officials informed her that she was able to work; they could not see that anything was wrong with her. She was not physically handicapped in any obvious way, and she was able to carry on an ordinary conversation and follow routine instructions without any apparent difficulty. She applied for benefits a second time and was denied again. She then managed to qualify for welfare, but only for one month. She received $204 for that month. She also succeeded in getting $80 a month in food stamps, which continued until December 1986.

When she was forced to move out of her sister's apartment and there were no more disability insurance checks, an elderly woman of 77 invited Mrs. Goode to live with her. The woman asked for $150 a month rent, but when Mrs. Goode's welfare payment stopped after one month, the woman allowed Mrs. Goode to continue to live with her without paying because she wanted a companion. For over a two-year period, Mrs. Goode's only income was the $80 a month in food stamps. If she had not been offered free housing, she would have been on the street. She stressed that she came very close to being destitute and homeless.

Extreme Despair, Declining Mental Health Lead to Eligibility

Because she had been denied Social Security benefits, Mrs. Goode looked in the yellow pages of the telephone directory and found a social security lawyer. The lawyer, together with the rehabilitation counselor and psychiatrist to whom he referred her, succeeded in accumulating enough evidence of disability to ensure Mrs. Goode's eligibility for benefits. That process took two years. Mrs. Goode was entitled to **Social** Security benefits as the result of a psychiatric evaluation, for which the psychiatrist and rehabilitation counselor pressed. Mrs. Goode had become severely depressed and withdrawn. The rehabilitation counselor noted that Mrs. Goode was not entitled to benefits until she "almost went completely crazy." Before that time, she was considered too functional to qualify for benefits. When she became more disoriented, the health professionals were able to classify her condition to fit the eligibility requirements of the Social Security Administration. Her type of organic impairment, alone, was not enough to qualify her for benefits, even though she could not remember things, could not function at a job, and was extremely dizzy and nauseous all the time. The rehabilitation therapist, in conjunction with the psychiatrist, prescribed medications to control Mrs. Goode's anxiety as well as the dizziness and nausea brought on by the vertigo. In 1987, SSDI payments began at $435 a month, with SSI at $88 a month. At the time of the interview (1988), she received SSDI at $518 a month and SSI at $77 a month. The food stamp money ended when the SSDI payments began.

Functioning "Just Barely"

In May of 1987, the elderly woman with whom Mrs. Goode lived died and left the house to her adopted daughter. The daughter and other family members had keys and were coming in at all hours of the night, upsetting Mrs. Goode terribly. The rehabilitation counselor arranged for Mrs. Goode to move to nearby government-subsidized housing in June 1987. Mrs. Goode felt lucky to have a studio apartment for $220 a month at the time of the interview. The rent is adjusted annually in conjunction with the Social Security payments. Mrs. Goode reported that she finally felt settled and that her medications were under control. She felt she was functioning, "but just barely." She became a Jehovah's Witness about six months after the injury and said her religion, along with Bible study and church activities, gave her the strength to go on living. She planned to be more involved in church activities in the future. Through the rehabilitation counselor, she began peer counseling with other brain-damaged adults. This opportunity to continue to help other people as she did in her former employment was important to Mrs. Goode.

People with hidden disabilities, such as certain types of brain damage, are discriminated against by federal programs simply because the lack of functional ability is not apparent to system officials. To be eligible for benefits, disability must be obvious, and in the case of Mrs. Goode, allowed to increase in severity. Federal guidelines stipulate extreme illness and destitution in order for an individual to qualify for benefits.

Trauma to the Self

Burns and Disfigurement

Approximately 60,000-90,000 people are hospitalized in the United States each year for the treatment of bum injuries. With medical advances in burn care, people are surviving severe burns covering over 70 percent of the body surface. Burn patients undergo multiple operations for skin grafting and repeated admissions to hospitals for reconstructive surgery, and they live with permanent scarring. A severe burn is considered by many to be the most devastating injury a person can survive (Locke, Rossignol, Boyle, and Burke, 1986).

Numerous studies of severely burned patients point to the deep and complicated emotional reactions that accompany burns (for example, Andreasen, Noyes, Hartford, et al., 1972; Bernstein, 1975; Hamburg, Artz, Reiss, Amspacher, and Chambers, 1953; Noyes, Andreasen, and Hartford, **197l).** Facial disfigurement caused by **a** severe bum potentially alters consciousness more drastically and creates more serious emotional problems than other forms of disability because the face represents oneself, one’s essential being, more than any other part of the body. A burned and unrecognizable face creates a metamorphosis in a profound sense, as one’s identity is deeply threatened by the physical transformation. The following case presents one woman’s struggle and method for coping with that horrible transformation.

Laura Frank -- Loss of Her Face, Loss of Her Self

Pulling up to a stop sign, with her boyfriend in the driver’s seat of the car, was the last thing Ms. Frank, aged 35 at the time, remembered about the night in 1977 when her injury occurred. She was told later that a car rammed hers, and that the explosion from the gas tank knocked both Ms. Frank and her friend unconscious. A passerby pulled her friend out. She was left in the car for a time because the flames obscured her. Someone finally saw her and pulled her out. She recalled waking the following morning in a hospital bed, surrounded by doctors and nurses who told her where she was and what had happened. Until they spoke to her, she thought a nuclear bomb had dropped.

Thirty-five percent of Ms. Franks face, upper body, arms, and hands were burned. She was hospitalized for two and a half months, during which time she received the standard excruciatingly painful treatment for bums. She recalled, “After breakfast every day, they gave me my morphine, and then took me in for the tubbings, the baths that every burn patient gets to promote healing and prevent infection. Every time they put me in the wheelchair to take me down there, and pulled the sheet over me, it was like knives in my shoulder." During the same period, she underwent surgery several times for skin grafts and had the fingers on her right hand amputated. She was right-handed. The initial skin grafts on her face were not successful and had to be done again.

Afraid of, Devastated by Frightening Image of Self

Ms. Frank was afraid to look in the mirror. During her initial hospitalization, she avoided all shiny surfaces and managed never to see her reflection. In retrospect, she stated that it was a real disservice that the social service, psychiatry, and nursing staffs never confronted, supported, or guided her in dealing with facial disfigurement. On the day the nurse drove her home, she went into the bathroom and saw herself for the first time. She began screaming hysterically. For the first time, she wanted to die. She did not recognize her own face. She stated that if the nurse had not been there, she would have gone "stark raving mad." The next day, in the tub room at the hospital, she lost control of her emotions as never before. She recalled crying, screaming, and wanting to die. At that moment, she recalled, she came close to a psychotic breakdown. The hospital staff got her out of the tub and in to see a psychiatrist. That was the first time the hospital offered her psychological counseling of any sort.

When she was first discharged from the hospital, Ms. Frank went to live with her boyfriend. After a month, he told her he wanted to date other women, and that he could not take the responsibility of her burns and care. She was absolutely devastated by his behavior: "I felt I would never have another relationship. Who would even want to look at me let alone hold me and kiss me? How was I ever going to be part of life again. I had a lot of anger and grief." She had no family in California and moved in with a woman friend with whom she lived from June 1977 until April 1978. For the first four or five months after hospitalization, Ms. Frank also had a live-in nurse who dressed her, fed her, and drove her to the hospital for the daily tub baths and occupational therapy treatments she still required. Those gradually were reduced to three times a week, then twice a week.

Insurance and More

Ms. Frank was a junior high school teacher of English and journalism. The insurance plan through her school district covered all of her initial hospitalization costs and all of her many subsequent surgeries. The insurance covered 80 percent of the outpatient burn and occupational therapy treatments, which went on for months after she was discharged. Some of the 20 percent of the remaining costs was paid by her boyfriend's insurance. The rest came from her savings. She could not go back to work for the remainder of the academic year nor the next year, 1977-1978. The superintendent of her district, where she had been teaching for eight years, made the personal decision to pay one-half of her salary during that entire period. This payment was not stipulated by her contract.

Support from Psychologist, Friends

Ms. Frank then began to see a psychologist who helped her deal with her burn scars, confront her disfigurement, accept her right hand with no fingers, and regain her sense of self-worth. Because the psychologist with whom she worked did not have a Ph.D. degree, Ms. Frank's medical insurance would not cover the therapy costs. Her friends got together and paid for her therapy, which went on for about a year. Ms. Frank said that her friends were extraordinarily supportive through the entire recovery process, and that she owes whatever emotional strength she found to their constant support.

Reconstructive Surgery

There were many surgeries. Ms. Frank had face reconstructive surgery in November 1977. In February 1978, she elected to have joint replacement surgery on her left fingers. She wanted to regain the use of those fingers, but later felt that the surgery did not help and may have hurt her in the long run. She then had more surgery on her eyes, her nose, and her right hand. That hand surgery enabled her to have a strong grip, and she resumed writing with her right hand. All surgeries were covered 100 percent by her insurance. She had lots of emotional support, always going home with a friend for a week or two following the surgeries.

Healing -- A Horrible Appearance

Ms. Frank went back to her teaching job in September 1978. She scheduled the surgeries over the school holidays. During the first two years of resumed teaching, she wore a heavy, tight mask over her entire face and a covering over her right arm. They are used to reduce the severity of the scarring while the grafts heal. She was terrified of what the students at school would think of her in her mask because she looked so awful. When it was time to take the mask off, she was terrified again of what everyone would think of her face. None of her fears were realized however; everyone was nice to her. After reentering school, Ms. Frank prepared an entire curriculum to educate staff and students about burns, burn treatments, and facial disfigurement. She said the program helped people cope with her, and her with them. She went on to teach in another junior high school and in a high school for another three years. Each time she changed schools, she presented her program on burn education. She decided she wanted to spend more time developing burn and disfigurement curriculum for the schools.

Winning Lawsuit Changed Life

During the same period, Ms. Frank was involved in litigation against the automobile company. The lawsuit was started immediately after the injury by a lawyer who was a friend. The suit was settled in 1980. She received close to one million dollars in a lump sum payment. The settlement enabled her to buy a larger home. Ms. Frank wanted to develop a reentry curriculum to be used in schools for children or staff with burns and other disfiguring disabilities. The settlement enabled her to take time off from teaching to do this. She initially took a one-year leave of absence, but has not returned to teaching since.

Ms. Frank’s curriculum development work began with a grant from a private foundation. In 1986, she began working as a paid staff member with the county rehabilitation medical center, creating reentry programs for disfigured children that are used now by school districts all over the state. She has added a “corrective cosmetic and total disfigurement center,” to give practical advice about how to make the most of one’s looks for those with severe burns and disfigurement caused by injury or illness. She was motivated to do this work by the absence of advice and care for coping with disfigurement. She said burn centers simply do not address the issue of community reentry or the severe self-image problems of burn victims. The lack of psychological counseling in the days and months following Ms. Frank’s injury proved to be profoundly devastating. Winning a sizable lawsuit enabled her to devote her life to making sure other disfigured individuals do not undergo emotional trauma due to lack of professional support. This case illustrates the fact that emotional and psychological support following an injury are absolutely necessary, and that the need for support may continue for years.

Attendant Services

Who is in Control?

More than 7.7 million people or 3.3 percent of the United States population require some help from another person to accomplish normal, everyday tasks because of functional limitation. Age is a significant factor in determining the need for personal assistance. Only

2.2 percent of the population aged 18-64 needs assistance, but more than 16.8 percent of the population over age 64 requires such assistance (World Institute on Disability, 1988).

Disabled individuals who associate themselves with the independent living movement measure independence -- that most cherished national value -- not by the number of tasks one can do by oneself, but by the quality of life one can have with appropriate assistance. In the context of this movement, aid is considered a civil right, an entitlement that permits the individual with a disability to participate in work, recreation, family, community, and political life. Attendant services are viewed as indispensable to participation in society and thus are considered an inalienable right.

The two cases presented below represent extremes in the exercise of control. The first, Mr. Morgan, controls his services by hiring, training, firing, and determining the wages of his personal assistants. He perceives his attendants to be extensions of himself. They work for him, and their work enables him to consider, at age 23, an education, a career, and a productive future. The second case, Mrs. Chapman, is at the mercy of the personalities and behaviors of the attendants sent to care for Mr. Chapman by a social service agency. Rather than being freed by the attendants to participate more fully in the life they once had, the Chapmans have become limited to an existence of coping with the attendants themselves. These cases represent the extremes of a continuum and illustrate how attendant services can be an opportunity for the bolstering of self-esteem and the control of one's destiny, or can seriously erode self-respect and autonomy.

Bart Morgan -- His Whole Life Ahead of Him

In 1981, at the age of 17, Bart Morgan was thrown off his motorcycle while speeding. He severed his spinal cord between the second and third vertebrae and was left quadriplegic, able to move only the fingers of his left hand and dependent on a ventilator to breathe. Mr. Morgan, who was in the Midwest visiting his father at the time, was hospitalized for three months and then transferred to a hospital in the San Francisco Bay Area where his mother and three siblings resided. He was hospitalized there for four months. He had numerous surgeries for infections in his neck resulting from the fracture and quadriplegia. During the entire seven months of hospitalizations, he was medically unstable and not sure if he would live. When his life was no longer in danger, he was transferred to a rehabilitation hospital where he stayed for almost a year, participating in an active rehabilitation program. He returned to his mother's home in 1983 and has lived there since. He requires 24-hour-a-day Licensed Vocational Nurse (LVN) care, which he will need for life.

Medicaid Waiver Prevents Institutionalization

The family's private health insurance covered all of Mr. Morgan's medical, rehabilitation, and LVN care costs until 1985, when the $1 million coverage ran out. At that point, he applied and became eligible for a Medicaid waiver to cover his 24-hour LVN care, at $15.75 an hour. Medicaid waivers allow states to develop demonstration projects to serve people who would otherwise be in hospital or nursing home beds. Mr. Morgan is fortunate to be included in one of the few demonstration programs in the country.

Learning to Live With Personal Assistants

At the time of the interview, Mr. Morgan had been receiving Medicaid funded attendant services for two and a half years. For the year before that, his private insurance had paid for his attendants. Until approximately six months before the interview, Mr. Morgan's time at home -- three and a half years – was spent mainly in learning to recruit, train, and get along with attendants. By the time of the interview, he had acquired as much autonomy as possible in his home environment by creating and managing a smoothly running schedule for himself using his attendants.

When Mr. Morgan was discharged from the rehabilitation hospital to his home, a rehabilitation counselor motivated him to become an activist in his own care and to take charge of both his current condition and his future life. Over time, that counselor became for Mr. Morgan a model of the independent living movement philosophy and a father figure as well. Mr. Morgan stressed that the counselor helped him grow up, learn about his body, and understand other people: "I learned from him that my nurse is an extension of me. If I go out there and fix myself lunch, the nurse helps me fix lunch. The dishes we use are our responsibility to wash and put away. It is real clear, and it is a common courtesy." Mr. Morgan underscored the independent living philosophy as he further explained, "I was taught by the rehab counselor how to train my nurses. I had to learn how to be the boss, how to be diplomatic when personality conflicts arose between me and the staff, or between my mother and the staff. I've had 40 nurses since I came home. When I interview them, we go through everything so I don't waste my time, their time, or the state's money to train them."

Advocate for Assistants

Mr. Morgan acts as an advocate for his nurses, “If you want good people, you have to pay for them.“. He interviewed representatives from several agencies who accepted Medicaid contracts before finding one that would pay the nurses a salary of $10 an hour. He stated that Medicaid pays the agency $15.75 an hour for the LVNs, but he had to negotiate the $10 an hour salary. There is no industry-wide or agency-wide policy on attendant salaries.

On to Education and Job

In 1982, when Mr. Morgan turned 18, his SSI benefits began at $450 a month. He used part of that money to pay rent, “to help out my mom,” who worked full-time as a supervisor in an electronics plant. The rest was his own spending money. He spent two years attending the local community college, taking general education courses. His education there was financed by the State Department of Rehabilitation. At the time of the interview, Mr. Morgan was working part-time as a peer counselor for other ventilator-dependent quadriplegics. He said he was lacking direction in his education and was ready for specific job training. He was searching for a state-financed program that would train him for computer work, which he physically could do (with the help of an attendant) and in which he was quite interested. With his nursing care under control, Mr. Morgan had entered a period of frustration concerning the next hurdle in his life, job training and employment. Mr. Morgan needs a ventilator to help him breathe. He can only move two fingers on his right hand. Yet he has learned to take control of his bodily functions and daily routine through his attendants. Now, his goal is to expand his horizons by entering the workplace -- with his attendants as extensions of himself.

Vulnerability and Dependence After a Fall

The tendency to fall is a serious problem associated with aging. 72 percent of deaths due to falls in the U.S. occur in the 10 percent of the population that is aged 65 or older. About a third of this age group living at home will fall each year, and about 1 in 40 of them will subsequently be admitted to a hospital. Repeated falls are a common reason for admission of previously independent elderly individuals to long term care institutions (Rubenstein, 1983). This example illustrates the response of Mrs. Alice Chapman to the ramifications of her husband’s fall. Managing the care of her disabled spouse plunged Mrs. Chapman into a position of vulnerability and dependence on the social service system.

One year after he had a stroke, Mr. Chapman, aged 78, fell while walking in his kitchen and fractured his hip. From the time of his stroke until that moment, Mr. and Mrs. Chapman had lived in their comfortable, two-bedroom apartment, up a flight of stairs. As a result of the hip fracture, Mr. Chapman was hospitalized for about six weeks. He had his hip pinned surgically and then spent weeks in physical therapy attempting to relearn to walk. He complained of intolerable pain and did not resume walking. At the time of his hospital discharge, the hospital social worker informed Mrs. Chapman, who was able-bodied and relatively healthy, that her husband would now require a round-the-clock attendant at home because of his inability to walk even to the bathroom. His generally weakened condition made him unable to care for his personal needs, which included the use of a catheter.

The hospital discharge planner referred Mrs. Chapman to a local agency from which she hired for her husband one attendant to work Mondays through Fridays, and another for the weekends. Medicare does not cover attendant services, nor do 'Medigap' private insurance policies. Long term care insurance, which is now beginning to serve elderly people by paying for expenses that Medicare will not cover, has many restrictions and conditions on attendant service coverage and will not pay for it in most cases. Mrs. Chapman paid for 24-hour-a-day care. The Family Survival Project in San Francisco estimated the average cost of a live-in Nursing Assistant or Home Health Aide to be $110-120 a day in 1987.

Alice Chapman's Story

Since Mr. Chapman's return from the hospital (three months prior to the interview), Mrs. Chapman's once active and community-oriented life had shrunk to the narrow focus of dealing with her husband's attendants and the uncertainty and crises they caused. The weekday attendant began work as soon as Mr. Chapman returned home. Mrs. Chapman reported that this attendant was a "prima donna." He did not like their children to visit and said they were interfering in his care of Mr. Chapman. Whenever friends and family came by, the attendant was always there, standing by Mr. Chapman's wheelchair saying, "Show them all how high you can pick your hand up," or "He had this many units of urine today," which made Mr. and Mrs. Chapman feel degraded.

The weekend attendant, in contrast, was very cordial. The Chapmans felt comfortable with him. But after only two weekends, he telephoned Mrs. Chapman from jail, and asked her for $250 to get him out. He did not return to work, but the weekday attendant offered to work straight through until Mrs. Chapman found another attendant for the weekends. She reported, "He worked for nine straight days, and then he had a fit; he just went crazy and he became awful. He became abusive and was absolutely impossible. Meanwhile, I got somebody else from the agency for the weekends. I never liked him. My husband was terrified of him. On the first Sunday the new man was with us, he had just made up my husband's bed and put him back in it, when my husband soiled it. He let out a blue streak of swearing at my husband. It was degrading and awful." She finally found another weekend attendant.

From Bad to Worse

Things were getting worse with the weekday attendant. Mrs. Chapman reported, "I had a handyman over to fix things, and I decided I wanted my privacy so I had a lock put on my bedroom door. The attendant said to me: 'Why are you doing that? Don't you trust me? First your children interfere with everything I do, and now you don't trust me.' But the last straw was when I called the doctor, to talk to him about my husband's condition. After we had talked for a few minutes, I said, 'I'll get the attendant on the line to talk to you about medications; he takes care of that.' He had been listening on the extension phone anyway, and said, 'I'm right here.' They started to have a conversation, and I interjected something, and he yelled at me through the extension phone, so that the doctor was right there to hear. He said, 'Mrs. Chapman, how can you interfere? The doctor is a busy man, and I'm handling this, I'm taking care of this.' I hung up the phone, but I was boiling, absolutely boiling, so humiliated." After he left, she took the attendant's clothes and paycheck to the agency, and he never came back. The new weekend attendant began to work four days a week and a friend of his worked the other three days. Mrs. Chapman summed up her ordeal, "Until these two arrived, it was an absolute nightmare."

Even people who can afford to pay for attendant services cannot get the services easily or readily. The Chapmans' situation illustrates the dangers of being dependent upon the private, for-profit marketplace. This case is a powerful example of why this country needs a long term care system that responds to people's needs for appropriate assistance in the home.

Impact On the Family

Mothers and Children

Twenty million children in the United States have a chronic physical or mental condition; 3.2 million of them are limited in daily activities because of the disability. Mothers serve as the primary caregivers for these children, whether or not the mothers are employed outside the home. Caregiving for disabled children has enormous emotional costs; the most negative consequences include depression, anxiety, frustration, and feelings of helplessness (U.S. House, 1988). When injury resulting in severe, permanent disability occurs, the entire family is affected. Though the injury physically impairs only one person, it has many impacts on all family members. The disability will change the schedules, daily activities, and responsibilities of those who live with or are responsible for the injured person. Roles and places of residence may be altered. The changes may be subtle or dramatic, and they may be permanent. Change is experienced by the individual as loss -- loss of predictable patterns of daily living, free time, recreational and employment opportunities, money, sleep, and independence. More frustrating, frightening, and disappointing is the loss of the injured person as a fully functioning family member. The primary caregiver of the injured person potentially experiences the most disruption, anger, guilt, and resentment of any family member. Change, loss, and the fact that there is never a return to ‘normal’ are the noneconomic, yet absolutely real, costs of injury to the family.

Mothers’ Perspectives: Disability All-Consuming

Four stories were told by mothers of severely injured children (all male). Two adult children, aged 18 and 21 at the time of their injuries, sustained severe brain damage, making them unable to be left alone safely and dependent on their families for the rest of their lives. One three-year-old suffered severe brain and central nervous system damage as a result of nearly drowning. He will be wheelchair-bound and unable to speak or care for himself in any way for the remainder of his life. A sixteen-year-old broke his neck in a school-sponsored wrestling match and became quadriplegic. He died 18 months later of complications resulting from the quadriplegia. All four mothers devoted their lives to caring for their disabled children with as much common sense and mental well-being as seems possible.

Their stories illustrate the fact that money and services are critical to caring for a severely disabled child. No one in this study group was independently wealthy. Legal settlements enabled three of the families to survive what otherwise would have been financial difficulty or devastation from the injury. Moreover, the settlements made it possible for two of the parents to bring their children home to a changed and accessible environment, enabling the patient to be in familiar surroundings and be nurtured by family members. The three mothers each emphasized that they would have become bankrupt or completely unable to cope had they not been awarded a sizable sum of money. The fourth case is an example of the parental stress and lack of adequate care and treatment for the injured person that results from inadequate funds. Carolyn Vash writes of family members who become "casualties of the system" (Vash, 1981, pp. 59-60). This occurs when family member needs for practical or emotional support either are ignored by individuals in health care or social service agencies, or are not met because appropriate services do not exist. Of the four case studies in this group, two can be described as casualties of the system, one in an extreme form.

Caring for Brain-Injured Adults

It is estimated that each year in the United States, 410,000 people sustain brain injuries. While the great majority experience good recovery, approximately 17,600 do not. Of these, over 10,600 have a moderate recovery, 5,000 are left with severe impairment, and 2,000 remain in a permanent vegetative state. Approximately half of these injuries are sustained in motor vehicle crashes, about 20 percent from falls, about 17 percent from assault (about 5 percent from firearms), about 10 percent from sports and recreation, and the rest from other blunt trauma (figures extrapolated from Kraus et al., 1984.)

Two of the mothers' stories share certain characteristics. At the time of the injuries, their sons were about the same age, 18 and 21, and were both employed and living on their own. Both became severely brain-damaged. Though their mothers placed them in sheltered housing environments for a time, those situations were not entirely appropriate, and both young men eventually returned home to live with the family. Both sons have needed nearly constant supervision since the injury. Both mothers have been divorced for many years and have worked outside the home to support their families. They have borne the full burden of their sons' disabilities without financial or emotional support from a spouse or ex-spouse.

The two stories also differ in several critical ways. One mother, Mrs. Smith, has four other, healthy children who rallied round her and gave their full and constant physical and emotional support to their disabled brother. The other mother, Mrs. Jones, has one other child, a daughter, who married shortly after her brother was injured and moved to a different city. Thus, the burden of care was placed completely upon Mrs. Jones. Secondly, Mrs. Smith won a legal settlement that permitted her to buy a large, comfortable home so that the entire family could remain together and so that Bobby, the brain-damaged son, could live in a normal family environment. Mrs. Jones, without any familial support, initiated but did not win a lawsuit, and she has struggled to find housing, employment, and care for her son from the time of the injury to the present, 15 years later. Third, Mrs. Smith is a practicing registered nurse. Her professional knowledge enabled her to make informed decisions about her son's care that were also appropriate for the family. Looking back, she felt all her decisions were the right ones, and that her son's best interests were served. She said that her medical knowledge made it possible to cope with the uncertainty of her son's recovery. Mrs. Jones, a secretary and writer, had no medical training to guide her through the maze of decisions she had to make on her son's behalf. She said repeatedly that she did not know anything about rehabilitation, brain damage, or community resources, and that nobody told her anything about these things. She felt her son suffered because of her lack of knowledge and that he did not recover as much as he might have, had he been given more aggressive early treatment and more consistent care over the years.

Bobby Smith -- A Family Rallies Around

In October 1985, Bobby Smith was working at a California ski resort; he has no recollection of what happened to him. Apparently, he backed into, and fell, 13 feet through a door at the top of a tramway. He was 21 years old. He was alone at the time of the fall and was found perhaps 20 or 30 minutes later, unconscious. 'In extremis,' he was taken to the nearest hospital, a small facility. He had an epidural hemorrhage. Doctors performed an emergency brain decompression, a nine-hour procedure. Bobby was in the hospital for two months. All hospitalization costs and surgeons' fees were paid for by Bobby's workers' compensation.

Bobby is the fourth of five children. At the time of his injury, he was living near the ski resort with one of his sisters. Two brothers were living in a large city, about a three-hour drive from the hospital. Mrs. Smith lived with her youngest child, a daughter who was still in high school, in an East Coast city. When the family was notified, the oldest brother, Alex, took over all caregiving and decision-making responsibilities until Mrs. Smith arrived from the East Coast. Alex said that his other brother, who was actually closest to Bobby, had a very hard time emotionally during the entire post-injury period and could not make any of the necessary practical decisions regarding Bobby's care. Mrs. Smith said that when she arrived after Bobby's two emergency surgeries, she thought he was going to die. He was on a respirator. Hospital staff asked her if they should discontinue the respirator, which she declined. "It really puts you in touch with your own mortality, and it is a terrible, terrible thing to have to face," she said.

Battling the Insurance Industry

Bobby's medical care was outstanding at the small hospital, Mrs. Smith thought. After Bobby had spent two months there, the family had to decide where to send him for rehabilitation. ‘That decision became our first battle with the insurance representative,” Mrs. Smith said. “He wanted to send Bobby to a hospital in Colorado, and we later learned that he owned a part of that hospital. He pushed us very hard, and even flew us out to see it.” But Mrs. Smith found that hospital no better than local rehabilitation facilities, and her biggest concern was keeping the family together during this crisis. She felt, along with all her children, that Bobby’s recovery depended upon his being near his family as much as upon his medical rehabilitation program. She decided to send him to a hospital in the San Francisco area where three of her children were living. She had planned to move to the area herself the following year when the youngest child graduated from high school.

Family Life Revolves Around Patient

Bobby was in the rehabilitation hospital for one year. During that time, Mrs. Smith flew out from the East Coast every month for six months until June, when her daughter finished school and they moved West. She began working full-time as a nurse on the night shift. She spent her days with Bobby in the hospital. Until she arrived, Alex went to the hospital every morning at 9:00 a.m., to be with Bobby for most of the day. He worked as a waiter in a restaurant during the evenings. When his mother finally moved to the area, he confessed his emotional exhaustion, and asked his mother to take over. Both Mrs. Smith and Alex are convinced that their presence and care for Bobby saved his life and enabled him to recover as much as he has.

Hospital Liability and Restricted Treatment

Bobby’s insurance covered all his medical bills at the rehabilitation hospital. He was medically unstable during periods. He was missing 40 percent of his skull. He had a pressure shunt inserted. He had plastic plates inserted in his skull to control the pressure shifts. Mrs. Smith reported that the hospital staff was afraid to do active rehabilitation with him because he was so unstable. They had liability issues, she reported. If Bobby fell during physical therapy, for example, hospital staff were afraid that the family would initiate a lawsuit, so they did not do active therapies and did not encourage him to begin to do things for himself. As a result, the family felt Bobby was not getting enough rehabilitation. So Alex learned how to do much of the staffs work, including inserting feeding tubes before Bobby learned how to swallow, and initiating therapeutic exercises. Bobby was in the rehabilitation hospital for one year.

Post-Rehabilitation Experience

The family had heard about a sheltered, transitional housing facility in the area for brain-injured people. They decided to place Bobby there, to try it out. Bobby lived in a condominium there and participated in a day treatment program complete with psychological nursing services and rehabilitation services. Bobby was the first patient in that facility. He was there for nine months. Mrs. Smith was commuting there once or twice a week, a two-hour ride on public transportation, while she was working full-time on the night shift.

The facility staff concluded they could not do anything more for Bobby at the same time that the family decided to take him home. Bobby had become like a small child, but the family believed he could learn to do things for himself. The family wanted to control his re-education and did not want him living away from them. They had thought all along that they could provide the best care and a situation in which Bobby could learn and thrive. If they were not with him, they felt his functional abilities would deteriorate and that he would suffer emotionally. They were renting a four-bedroom house in San Francisco with only one bathroom, which was upstairs and too small for a wheelchair.

Winning a Lawsuit Freed the Family to Have a Home

On the day of the injury, Bobby’s lawyer referred Alex to other lawyers who began a lawsuit against the company that built the door through which Bobby fell. They settled out of court nearly two years later, in July 1987. The settlement is an annuity that pays Bobby a monthly check of $5,057. It will pay $7.5 million over Bobby’s lifetime. The settlement freed the family to decide to care for Bobby permanently. They would never have had the money for a home without the legal settlement.

Liability Paranoia

As soon as Bobby returned home from the transitional facility, Mrs. Smith took him to a neurologist with the goal of taking him off medications. The family realized he was overmedicated both at the rehabilitation hospital and at the transitional facility. They referred to this fact as a “catch 22.” It is well known that certain kinds of patients, especially those who are brain-damaged or mentally ill, are frequently heavily medicated because of liability concerns. Sedated patients are not likely to run off or injure themselves, but they are not able to achieve maximum rehabilitation, either. Bobby was wheelchair-bound while at the transitional facility. He was having seizures, a common result of brain damage, about once a month. After the neurologist reduced his seizure medication by half, he still had about one seizure a month, but was able to function much more effectively.

Gambling on Good Health

SSDI payments began for Bobby in September 1987. Mrs. Smith applied when he came home, and received one year in additional retroactive payments. He receives $97 a month. He will be eligible for Medicare after receiving SSDI for 24 months, and Medicare will pay 80 percent of his medical bills for life. The “catch” or “gamble,” as Mrs. Smith and Alex expressed it, is that they currently have no health insurance for Bobby. The family is taking a calculated risk that Bobby will not fall, have another brain injury, or have a major acute illness in the two-year period before Medicare payments begin. All the family members save as much money as they can against the possibility of a catastrophic illness for Bobby.

The entire family has become involved with the community brain-injured support network. They find support group meetings very helpful. Mrs. Smith was recently asked to serve on the board of the network. She feels lucky when she compares her experience to other stories she hears about brain injury. She emphasized that the whole family was grateful to be working and able to support themselves and Bobby. The settlement enabled them to buy the perfect house for their needs and to keep the family intact. Bobby’s condition has improved over the years. Their risk is that he will incur a major medical expense before the Medicare payments begin. Again, winning a lawsuit greatly enhanced the quality of life for every member of this family. Federal regulations regarding the two-year waiting period for Medicare payments could potentially undo their security.

Stan Jones -- Falling Through the Cracks in the System

In July 1973, the automobile in which eighteen-year-old Stan Jones was the passenger was hit by a speeding car driven by a teenager with 22 moving traffic violations on his record. Stan was thrown from the vehicle and instantly knocked unconscious. Aside from the head injury, he suffered only minor cuts and bruises. Police witnessed the crash and rushed him to a hospital.

No Private Insurance

Stan was a patient at a trauma center for several months, and in a coma for the first six to eight weeks. Because the family had no private insurance, he was placed in a city-run convalescent hospital where “he was with old, demented men mainly,” Mrs. Jones said. She felt that was a terrible situation, and that Stan would "definitely go crazy there." After several months, she found another placement for him in a suburban convalescent and rehabilitation hospital where he stayed for ten months. For the first four months following the injury, Stan could not eat; he could not speak for ten months. When Stan was moved to the suburban rehabilitation hospital, Mrs. Jones moved also to be nearer to him. She felt he did not get enough rehabilitative therapies there because he had behavioral problems resulting from the brain damage. He was very disruptive, causing the staff to prefer to leave him alone. Mrs. Jones said that during the first year after the injury, no one told her where to go for adequate rehabilitation for her son. She made every decision in a vacuum and, without appropriate information or education, learned how to interact with and care for her son. All of Stan's acute care and rehabilitation costs were covered by Medical.

Impact on a Sibling

The family also consisted of a daughter, one year younger than Stan, who was out of town at the time of injury. "Our family was not able to pull together after this," Mrs. Jones said. "My daughter recoiled from the whole thing; she did it for her own survival. She married a year after the injury, in response to it. That marriage lasted four years. She pulled back emotionally from me and from her brother."

Ramifications on Employment

Divorced for many years, Mrs. Jones had worked as a secretary and raised the children on her own. She did not work at all for the first six months after her son's injury. Then, when she got a new job, she could not concentrate and was fired. She said that she would have quit anyway. Her doctor arranged for her to receive disability insurance for a time and told her that it was best if she did not attempt to resume work.

Effects of Brain Damage

In the middle of 1974, Stan was discharged from the rehabilitation hospital to home. By then he could walk, dress himself, and talk, but he could not be left alone. He was hallucinating some of the time. He would close the curtains of the house and play records. He had trouble getting into the shower; he was very hypersensitive, and the water irritated him. Mrs. Jones stressed that no one told her that his behavior was due to the brain damage. Nobody told her what to expect; she had to "learn everything from scratch." She was overwhelmed. At the time of the interview, 15 years post-injury, his behavior is still unpredictable.

He will scream out regarding something he does not like or something that upsets him. He has limited judgment and control.

No Appropriate Housing or Treatment

After two years of having Stan at home with her, Mrs. Jones realized she could not care for him adequately, or cope with the situation emotionally, so she placed him in a half-way house for mentally ill people. This was the best setting she could find for him, but it was not entirely appropriate. He lived there for 18 months, but he kept trying to leave by walking away. She emphasized how, at every stage, her son "fell through the cracks of the treatment and care system." There are no appropriate institutional settings for brain-damaged people.

In 1977, Mrs. Jones remarried and remained in the marriage until 1980. The husband arranged for Stan's eligibility and placement in a federally subsidized (Section 8) housing project. Stan moved into an apartment shared with a couple who were supposed to be his attendants. He lived there from 1977 to 1981.

A **Glimmer** of **Improvement**

Through the half-way house, Stan received a grant from a private foundation for an aide to go to his apartment to teach him the basic skills he needed to live independently. The aide worked with Stan for two and a half years, until the money from the grant was terminated. Mrs. Jones felt this was extremely worthwhile and benefited her son greatly. During this period, his functional skills improved. His gait almost returned to normal. His voice tone became more normal. He began to run for exercise and to read a bit. The private foundation also paid for Stan to attend a local private college once a week for two years. He went to a learning center there to work on regaining cognitive skills. Mrs. Jones felt this was very helpful. During that period, she spent much time with her son, "bombarding him with verbal stimulation, and just being with him."

In 1981, Mrs. Jones and Stan bought and moved into the house in which they currently reside. It is small and run-down, but adequate for their needs. Stan has a separate entrance to a small apartment downstairs, giving him a feeling of independence. Also in 1981, Mrs. Jones went back to full-time secretarial work, which she continued for six and a half years.

No Package for the Problem

While she worked, Mrs. Jones had various attendants come to the home to care for Stan because he could never be left alone. She always had difficulty finding attendants who would remain on the job. She has spent most of her time and energy organizing systems of care for her son. When a caregiver leaves, she begins all over again. The past 15 years have been one long attempt to cope with his care. ‘There was no package for this problem,” she said. Professionals simply could not help her out. Although the state and county, through MediCal, paid for Stan’s round-the-clock attendant care for the first two years, there was no major legal settlement to aid her in hiring the help she needed for his care when those payments ceased. She became a casualty of the system with no financial backing of her own to pay privately for services. Though she owns her own home, she and her son live quite marginally. Stan’s emotional and behavioral problems have become worse over the years because of his early lack of emotional care in the days following the injury. Stan realizes and is angry about how dependent he is on his mother. At the age of 34, he suffers emotionally because of his dependence and lack of productivity. Mrs. Jones is both fed up with having the full burden of his care and emotionally exhausted. But she stated that she would never abandon him. At the time of the interview, she had no financial resources to draw on beyond those to cover her most basic food and shelter costs, and there were no appropriate community services available free of charge for her son’s care or rehabilitation. She felt that her situation was truly hopeless.

Lawsuit Nightmare

The day after the injury occurred, an attorney friend referred Mrs. Jones to another lawyer who began a lawsuit. She said, ‘The entire situation was a nightmare. I had no idea what I was doing.” She hired a “top firm” but felt, in retrospect, that the attorney did not do an adequate job. She sued the California Department of Motor Vehicles and the city of San Francisco (in two separate offices) on negligence charges. The lawsuit went on for 11 years. Mrs. Jones won in the court of appeals but then lost in the California Supreme Court. In 1980, there was a $16,000 settlement from one of the automobile insurance companies. The lawyers received $8,000 of that as their fee. Later, she received $4,000 more. She used some of the money for a tutor for Stan, bought a car for herself, and saved some of the money. The $8,000 enabled her to put a down payment on the current residence. The legal proceedings finally ended in 1984. She received nothing. She felt that more money would have enabled her to give Stan a lot more rehabilitation in the first years after the injury and to place him in a private residential facility with vocational training. He would have become much more independent had he had that opportunity.

Mrs. Jones has none of the support needed to cope adequately with her son’s injury: respite and emotional support from family or friends, insurance to provide rehabilitation opportunities, and a legal settlement to improve the quality of family life are all lacking. Stan is an example of the disabled person who can benefit tremendously from a specially trained attendant. This service was temporarily provided to Stan by a private foundation, but could be part of the publicly funded long term care system.

Caring for Severely Disabled Children

Joe Campbell -- Trauma, Devotion, Death

In April 1984, Joe Campbell, aged 16, attended a school-sponsored wrestling match. Toward the end of the day, with the coach gone for a few minutes, Joe began playing around with a boy 70 pounds heavier than he. The boys did some moves for which they were not well trained. They both fell and Joe screamed. He had broken his neck and was instantly paralyzed from the neck down. The coach ran in and performed first aid. Paramedics took Joe to the nearest hospital where he remained for two days. He was then transferred to a rehabilitation hospital where he stayed for 14 months. He died 4 months later.

Joe was the youngest of three boys in the family. The others were 19 and 20 and were living at home at the time of his injury. Mrs. Campbell, a deeply religious Christian woman, worked two days a week at a church-sponsored nursery school. Mr. Campbell worked for a chain retailer; his gross income at the time of his son’s injury was less than $25,000 a year.

Long Hospitalization

Joe had 23 doctors who cared for him after he was injured. Mrs. Campbell felt that they all were good, and that her son received consistently excellent care from the entire health care team throughout his hospitalization. His medical problems were profound. He had pressure sores from his inability to move. He developed skin rashes, allergic reactions to different medications. He was on a respirator for the first seven months of his hospitalization. His inability to talk because of the respirator was extremely frustrating for family members, who desperately wanted to communicate with him.

Insurance Coverage

Joe’s medical care was covered by three insurance carriers. First, there was a group plan through her husband’s employer. But his union had negotiated only $150,000 maximum coverage. Mrs. Campbell told me she suffered a tremendous amount of anxiety when she was told initially that the $150,000 would probably cover only six months of Joe's care. After only three weeks, the hospital bills were $45,000, and she started to panic. The second insurance carrier was through the national letter carriers. Her husband had worked years before for the U.S. Post Office. Over the years, she had continued to pay the premium at $1,600 a year. That policy was the one that covered most of Joe's care, in spite of its one-year clause. At the end of one year, the insurance had paid about $400,000. Then, MediCal covered Joe's hospitalization for two additional months, until the family was able to bring him home. On the day of the wrestling match, Joe had paid $7 for $10,000 of insurance. With the loopholes Mrs. Campbell searched for and discovered, that third carrier contributed $20,000 toward Joe's care. But even three policies did not cover all his medical expenses.

Insurance Not Enough

The family needed more money for Joe's medical care than the insurance could provide, and Mrs. Campbell was advised to begin a suit against the local wrestling association. The settlement came to $100,000. The lawyer got a third of the settlement in fees, plus a few hundred dollars in expenses. Joe had just turned 18 by the time the settlement came through, and Medical, which had been covering his medical costs, received half of the net of the settlement. The family ended up with $33,000. They did not receive the settlement until April **1987,** after Joe had died. The grand total of Joe's medical care: $604,576.11.

The Complexity of Going Home

The family had to significantly remodel their home in order for Joe to be able to live as a wheelchair-dependent quadriplegic. They had a ramp built to the front entrance of the house and they needed to rebuild a bathroom, which required plumbing changes throughout the house. In addition, they added a room for Joe, off the kitchen. The total cost of the remodelling was $23,000. Mrs. Campbell explained that there was an enormous amount of red tape with the city planning department. She worked with an architect from the city housing department, a service subsidized by the city. In order to pay for the construction, she borrowed $17,000 from her parents. $7,000 of that was paid back to them from the legal settlement. Her parents refused to accept any more money. In addition, she used all the money in Joe's savings account; they borrowed against their life insurance; an aunt gave them $1,000, and the church set up a "homecoming fund" for Joe and raised $7,000 toward the cost of the construction.

Disrupting the Family

Joe's homecoming proved to be a major adjustment for the family. The younger brother very reluctantly gave up his room for Joe. The older brother, who was closest to Joe, was studying accounting at the time of the injury. He quit his course and has become depressed and without direction since. Joe was home for three months before he died. During that time, Mrs. Campbell had full responsibility for his care and was completely exhausted by it. In her attempt to hire an attendant, she interviewed scores of people, finding most of them inappropriate. She finally managed to hire a man for eight hours a day, five days a week, but he disappeared after the first month. She continued to interview others after that, but did not find anyone satisfactory. She did all his care herself, with some help from her husband. Her other sons did not help her out in any way. Joe's physical care was all-consuming, and the 'bowel and bladder" program had to go on every four hours. She did the 1:00 a.m. shift and her husband helped at 5:00 a.m., before he went to work, so she could sleep until 8:00 a.m.

Joe came home in June 1985. In September, he began school again at the public high school. He attended for four days, then got pneumonia, both bacterial and viral. Mrs. Campbell drove him to the hospital in the middle of the night, when he had great difficulty breathing. She was not sure he was going to make it through the night. But he lived in the hospital for three weeks. During that time, the family knew he was going to die. When he died three weeks later, Mrs. Campbell felt there was nothing left unsaid, and that her son "went home to God." During the final weeks of Joe's life, family members and close friends from church met in the hospital and planned his memorial service. Mrs. Campbell said this was extremely therapeutic and healing. She organized and hosted the memorial, attended by 200 people from all walks of Joe's short life: school, sports, hospital, doctors, and church. Insurance from three carriers was not enough to cover Joe's catastrophic injury, and the family needed to win a lawsuit to help pay for Joe's medical and related expenses. Most people are unaware of the enormous cost of a catastrophic injury.

Jason Stuart -- Youngest Child, Most Profound Disabilities

In 1982, three-year-old Jason walked out his kitchen door onto the back patio while his mother was not watching and fell into the swimming pool located several steps from the back door. At the time, Mrs. Stuart was married and had a six-year-old daughter and a five-month-old daughter. She and her husband ran **a** trucking and transportation business from their home. Mr. Stuart was out of the house when Jason fell into the pool and Mrs. Stuart was very busy with the business telephones. The six-year-old came screaming to her that Jason was in the pool. Mrs. Stuart found him floating on top of the water and estimated that he had been there at least 20 minutes. She jumped in, dragged him out, and ran screaming with him to the front of the house. Her neighbor, who happened to be a physician, came running out and attempted to resuscitate the child. Another neighbor called an ambulance. The child was pronounced Dead On Arrival at the nearest hospital. When they revived him some minutes later, hospital staff informed Mrs. Stuart that though he was technically alive, he would probably be blind, deaf, and permanently comatose.

Mother Initiates Rehabilitation

After Jason was hospitalized for seven weeks, Mrs. Stuart was told she could take home her still-comatose son. She had heard from a friend about a physician-designed rehabilitation program called Patterning, in which the coma victim is bombarded with stimuli. The program requires hundreds of volunteers. Its goal is to stimulate all the senses and bring the injured person out of the coma. Jason's doctors strongly discouraged Mrs. Stuart from trying this program and they were very pessimistic about Jason's prognosis. But Mrs. Stuart made the decision that she would do everything possible to revive her child and she began the Patterning program. She went to a local office, found out what she needed to do, and proceeded to gather all the materials (flash cards, pictures, other visual stimuli), which she paid for out of pocket. She also arranged for 125 volunteers a week to come to her house to run the program. For six months, from 7 a.m. to 8 p.m., she had volunteers who came to her home, touched and massaged Jason, read to him, flashed picture/word cards in front of him, and in many other ways stimulated the child constantly. During that period, she woke up every hour and a half during every night in order to turn the child over, preventing him from getting pressure sores.

Five months after the injury, the child emerged from the coma. Mrs. Stuart continued the Patterning program for another month. She felt his recovery was owed entirely to the stimulation he received from the program, which she stressed she carried out against her doctor's wishes. At six months after the injury, she decided to terminate the program. She felt at the time that it could continue to benefit the child, but she was too exhausted to recruit and train the many volunteers needed.

Extent of Disability

With severe central nervous system damage, including brain damage, the child was not able to learn to do the normal, developmental tasks of a three-year-old. He could do nothing for himself when he emerged from the coma, and now, six years later at age nine, still cannot do anything. He cannot sit up unaided, though he can hold his head up. He cannot control his movements and thus cannot feed himself. He is confined to a wheelchair when he is awake. Ironically, his vision and hearing are within normal limits and he can comprehend simple commands and sentences when someone speaks to him.

Insurance and Legal Issues

Eight months after the injury, Mrs. Stuart's insurance broker informed her that her health insurance carrier would no longer cover the huge medical expenses of the child and that the family would be switched to another carrier, which would give Jason the same coverage. For six months, the new carrier did not pay for any treatment or rehabilitation services for Jason, so he did not receive physical or speech therapy. Mrs. Stuart claimed that Jason would be less disabled today had he received those services in the early months following the injury. Mrs. Stuart retained a lawyer and sued the insurance carrier. She won the case and settlement back payments began in 1986.

About a year after the injury, Mr. and Mrs. Stuart became aware that they could collect from their home owner's insurance policy. Mrs. Stuart learned this after receiving misinformation for quite some time. In 1986, she finally received $500,000 for Jason's care, paid to him in monthly installments. The money is used for his needs, at her discretion. The bulk of it is in trust for him.

Catch 22 of Therapy

When he turned four, Jason began to attend the public school every week day, from 8:00 a.m. to 1:00 p.m. in a program for handicapped children. Jason has been in that school program for five years. Mrs. Stuart claimed the greatest strength of the school program was, and has always been, the speech therapy program in which Jason receives a lot of verbal stimulation. Over the years, he has learned to nod yes and no, and to recognize pictures, words, and commands. Although the school district technically provides a physical therapy program, the physical therapists cannot actually touch Jason during any exercises at all because of school district liability concerns. Mrs. Stuart deeply regrets this. She believes her child would have greatly benefited from 'hands on' physical therapy, which he does not receive. Like Mrs. Smith and Mrs. Jones, Mrs. Stuart also explained that she was caught in a "catch 22 situation" regarding physical therapy for Jason. To participate in the school district program, one cannot hire, even privately, a physical therapist. The reason given is that the school district does not want to duplicate services. She is legally prevented from getting physical therapy for the child if she wants to continue sending him to school. At the time of the interview, she had been fighting this policy with the school district for some time. She was convinced that Jason's overall physical condition was deteriorating because he could not get physical therapy. She said Jason had become much more stiff, especially in the past two years, and that his scoliosis (a common problem for wheelchair-bound individuals) had become more pronounced.

Divorce

In 1985, Mr. and Mrs. Stuart divorced, a common occurrence among parents of severely injured children (for example, see Nixon and Pearn, 1977, regarding near drowning). Mr. Stuart gave his wife no emotional support and his disabled son no physical help at all after the injury. He simply could not cope with his son's condition. Mrs. Stuart said that one day her husband walked downstairs with his suitcase and announced he was leaving. She had no idea he had planned to leave. She knew he could not cope with Jason's condition but was shocked that he would leave her and the children. The oldest child, then seven and a half, fell apart emotionally.

The family business had gone bankrupt several months after the injury. The divorce was settled with Mr. Stuart paying $500 a month in alimony and $1,200 a month for child support. This was not enough for the family. To meet the $1,500-a-month mortgage payments and other household expenses, Mrs. Stuart took on one, then two, then three part-time jobs. The alimony payments stopped about one year before the interview when Mrs. Stuart started a new relationship.

Remarriage

Mrs. Stuart remarried three months before the interview was conducted. At that time, Mr. Stuart wanted to stop the child support payments. Mrs. Stuart was furious at him for this and was determined that the payments continue. She was prepared to take him to court if the payments should stop. Her second husband works as an auto mechanic and brings home $480 a week. Mrs. Stuart said she would not give up the child support without a huge fight.

Emotional Toll on Siblings

Mrs. Stuart spoke about the emotional burden the injury placed on her two other children. Her eldest daughter was seriously affected by Jason's near drowning (Nixon & Pearn, 1977, report that emotional trauma typically follows the near drowning of a family member). Mrs. Stuart reported that about six months after the injury, the six-year-old confessed to her mother that the drowning was her fault. Her mother had told her to watch Jason. She felt guilty when she realized she had not been watching him and he fell into the pool. Mrs. Stuart tried repeatedly to explain that it was not her fault or responsibility. At present, that daughter, at age 12, is resentful of any help she has to give Jason. Mrs. Stuart felt she had neglected the oldest child over the years. The youngest child, now six, is more compassionate, Mrs. Stuart said, and she reads to her brother. But Mrs. Stuart worries that she may be learning-disabled. The father rarely comes to see the children and the oldest child misses him greatly.

Severe disability of a child, including a grown child, usually means that the mother must devote her life to the child's care. Extensive medical insurance and large legal settlements are essential to ensure that the family financially survives the catastrophe. A severe injury has profound, long-term ramifications on all family members. Individual responses are highly variable, yet divorce and the emotional instability of uninjured children are typical results.

Conclusion

A number of findings are consistent across these ten cases. Money is central to the well-being of the injured person and the family. The cost of serious injury goes far beyond initial medical treatment and includes housing, disability-related equipment, and long-term rehabilitation, education, and vocational training. For most individuals, the ability to financially survive a catastrophic injury depends on winning a large legal settlement in addition to having good private insurance coverage. Yet, even with a legal settlement and excellent medical coverage, it is realistic to be continually fearful of the cost of potential medical complications, follow-up surgical procedures, and future rehabilitation, housing, education, or job-training. The needs do not stop with medical stabilization; they continue for years or for a lifetime.

The consequences of severe injury have a far-reaching impact that goes beyond the economic cost. Profound disability affects all aspects of the survivors' existence for the rest of their lives, however long they may be. The disability disrupts, changes, and dominates family life forever. One family member, usually the mother or spouse, becomes the primary caregiver and devotes her life to the well-being of the injured person by calling upon all the personal and community resources of which she is aware. Emotionally surviving the burden of injury and disability depends on a supportive network for both the injured person and the primary caregiver from family, friends, health care professionals, and community groups.

Government benefits are set up on an either/or basis: disabled or employable; sick or healthy; indigent or ineligible for funds. Such inflexible criteria may not fit individual needs or unusual situations. Federal regulations are insensitive to the fact that many severely disabled people want to work and are capable of doing so. SSI and Medicaid have complex and variable eligibility criteria and are designed to provide benefits to the disabled at or below the poverty level. Services for the disabled are not consistently available across the country. In California they are more diverse, more individually tailored, and easier to acquire than in other places, especially in rural areas.

All people interviewed for this project thought there should be a "safety net," that is, they felt they should be able to rely on the "social service system" when a catastrophic injury occurs. They all expressed a "right" to more help with such extraordinary problems. They thought the social service system should be more comprehensive, more flexible, more supportive, and finally, more generous. Yet, in spite of their great need for the resources of society, all individuals illustrated characteristic American values: a determination to be self-reliant, a need to remain independent, and a profound responsibility toward disabled family members, regardless of the emotional and financial burden of that responsibility.