

MAINE STATE LEGISLATURE

The following document is provided by the
LAW AND LEGISLATIVE DIGITAL LIBRARY
at the Maine State Law and Legislative Reference Library
<http://legislature.maine.gov/lawlib>



Reproduced from scanned originals with text recognition applied
(searchable text may contain some errors and/or omissions)

STATE LAW LIBRARY
AUGUSTA, MAINE

A Report to the 112th Maine Legislature



Executive Summary

RD
131
.M34
1985

Maine Legislative Task Force on Head Injury

MAY 6 1985

STATE LAW LIBRARY
AUGUSTA, MAINE

A Report to the 112th Maine Legislature

Prepared by

Christine Gianopoulos
Polina McDonnell
Marilyn Russell
Karen Norton
Constance Morton

Human Services Development Institute
Center for Research and Advanced Study
University of Southern Maine

January 1985

for the

Maine Legislative Task Force on Head Injury



Maine Legislative Task Force on Head Injury

32 Winthrop Street, Augusta, ME 04330 Tel. 289-2141 TDD 289-3094

Co-Chairpersons

Rep. Thomas H. Andrews

Ms. Joan M. Jordan

January 25, 1985

The Honorable Charles P. Pray
President of the Maine Senate
State House
Augusta, Maine 04333

The Honorable John L. Martin
Speaker of the Maine House
State House
Augusta, Maine 04333


Dear President Pray and Speaker Martin:

On behalf of the Maine Legislative Task Force on Head Injuries, we are pleased to transmit our report to the Legislature. The report was mandated by resolve of the 111th Legislature and was prepared with funding from the Bureau of Rehabilitation, Department of Human Services. Additional support was provided by the Maine State Planning Council on Developmental Disabilities.

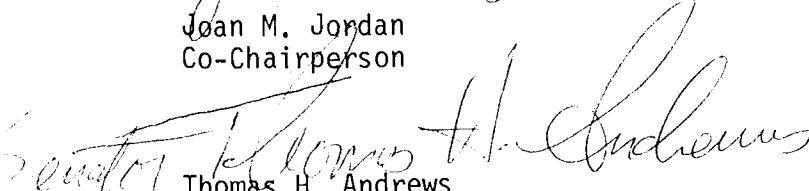
Each year approximately 1500 people with head injuries are discharged from Maine hospitals. Hospital costs alone for this group exceed \$3 million. The report documents steps we can take to significantly reduce the incidence of head injury and to rehabilitate head injured persons.

We would like to acknowledge the many Maine citizens who contributed to the work of the Task Force. They share with us a concern for the rising social and economic cost of head injury.

Sincerely yours,



Joan M. Jordan
Co-Chairperson



Thomas H. Andrews
Co-Chairperson



CONTENTS

	Page
Acknowledgements	i
List of Tables	ii
Members, Legislative Task Force on Head Injury	iv
I. Introduction and Summary of Recommendations for Legislative Action	1
Components of a Comprehensive Service System for Head Injured Persons	3
II. Who are the Head Injured?	4
A. Hospital Discharge Reports	4
B. Head Injury on the Highway	7
C. Head Injuries at the Worksite	8
III. Assessment of Existing Services and Service Needs	9
A. Public Hearings Testimony	9
B. Survey of Head Injured Individuals	13
C. Survey of Service Providers	15
IV. A Comprehensive Head Injury Service System for Maine	16
A. Prevention and Education	16
B. Trauma and Hospital Care	18
C. Brain Injury Unit	19
D. Community-Based Services	21

Acknowledgments

The Maine Legislative Task Force on Head Injury acknowledges the following individuals whose time, information and ideas contributed to the preparation of this report.

Nancy Ayer
Maine Association of Handicapped
Persons

Michael Fulton
Bureau of Rehabilitation

Sandra Johnson
Maine Health Information Center

Jim Montell
Bureau of Safety

Marge Fallon
Department of Educational and
Cultural Services

William Peabody
Bureau of Labor Standards

Mary Peirce
Palermo, Maine

Isabella Tighe, M.D.
Bureau of Medical Services

Members
Ad Hoc Head Injury Task Force

Advisory Board
Maine Head Injury Foundation

Members

Legislative Task Force on Head Injury

State Senator Thomas H. Andrews
Co-Chairperson
32 Thomas Street
Portland, ME 04101

Mr. Michael Opuda
Dept. of Educational
and Cultural Services
Augusta, ME 04330

Lieutenant Dale Hannington
Maine State Police
Dept. of Public Safety
Augusta, ME 04330

State Senator Larry Brown
44 Washington Street
Lubec, ME 04652

Mary Skorapa, M.D.
RFD 5A, Steventown Road
Gardiner, ME 04345

Diana Scully, Director
Bureau of Rehabilitation
32 Winthrop Street
Augusta, ME 04330

Mr. Ron Welch, Assoc. Commissioner
Dept. of Mental Health and Mental
Retardation
Augusta, ME 04333

Ms. Joan Jordan, Co Chairperson
Box 1400, Route 3
Wiscasset, ME 04578

Ms. Priscilla Dalton
32 Meridum Avenue
Kittery, ME 03904

Mr. Don Sanders
65 Patterson Street
Augusta, ME 04330

Mr. Paul Roane
50 Washington Street
Bath, ME 04530

Ms. Betty Adams, President
Maine Head Injury Foundation
P.O. Box 243
Livermore Falls, ME 04254

Kathy Goodwin, OTR
ALPHA I
169 Ocean Street
South Portland, ME 04106

I INTRODUCTION AND SUMMARY OF RECOMMENDATIONS FOR LEGISLATIVE ACTION

Each year in Maine an average of 1500 persons are hospitalized as a result of traumatic head injury. Traumatic brain injury is any combination of central nervous system dysfunctions, occurring at the brain stem level and above, which are the result of the interaction of the body and an external force. Each head injury results in a unique combination and degree of physical, cognitive and emotional disability. Memory, judgment, concentration and perceptual skills often are impaired. Physical problems include paralysis, seizures, vision and hearing loss, and headaches.

More than half of those hospitalized are under the age of 22. Typically, the person most at risk of a head injury is a young adult male involved in a car or motorcycle accident in which he was not using a seat belt or helmet. The majority of head injuries are caused by motor vehicle accidents and are preventable. Falls, assault, gunshot wounds and child abuse also contribute to the incidence of head injuries in Maine.

The aftermath of a head injury exacts a huge toll on the individual, the family and society. Stress on families and the high cost of publically funded rehabilitation, coupled with the lost earning potential of the head injured person, make it necessary for Maine to begin to address the needs of this group in a more systematic and appropriate way.

In April 1984, the Legislature passed a resolve establishing a Task Force on Head Injuries (Appendix I). The Task Force purposes are to:

1. Survey existing services available in Maine for persons with head injuries and their families;
2. review existing statutes, programs and rules which might be adopted to serve persons with head injuries;
3. undertake efforts to educate the public about the causes, prevention, treatment and management of head injuries; and
4. report to the 112th Legislature by January, 1985 on recommendations for administrative action, legislation and necessary appropriations.

Members of the Task Force were named in late August and began meeting in September. The Task Force built on the preliminary work of an ad hoc group who had been meeting since January 1984 under the auspices of the Bureau of Rehabilitation.

The Task Force conducted four public hearings; surveyed service providers, head injured persons and program and public policy in other states. Based on the findings of these efforts, the Task Force supports legislation and appropriations in four areas: prevention; education; health and social services; and financing.

Table I. 1
Summary of Recommendations for
Legislative Action

Prevention

1. Mandatory seat belt use in passenger vehicles.
2. Stiffer penalties for drunk driving.
3. Mandatory helmet use for motorcycles.

Education

1. Support educational opportunities beyond age 20 for disabled students.

Health and Social Services

1. Provide comprehensive head injury rehabilitation services, including home-based care, through more effective use of existing services.

Insurance

1. Mandatory motor vehicle insurance for all drivers.
2. Require health insurance policies sold in Maine to include coverage for home and community-based care.
3. Place a premium on motor vehicle insurance policies. Funds generated by the premium would subsidize the operation of community-based rehabilitation services for head injured persons. Since car and motorcycle accidents account for more than half of all traumatic head injuries, drivers as a group are much more at risk of becoming consumers of services.

The matrix on the following page outlines a comprehensive system of services for head injured persons:

Table I.2

Components of a Comprehensive Service System for Head Injured Persons

Service Component	Location	Number of Beds/ Clients Served/Yr	Provider	Estimated Cost		Existing Sources Of Funds	Additional State Funds for Next Biennium	
				1985-86	1986-87		1985-86	1986-87
Skilled Nursing Facility/Brain Injury	Portland	8 Short Term 4 Long Term 28 Clients/Year	Contracted Service	640,440	805,920	<ul style="list-style-type: none"> • Medicaid • Private Insurance • Other Third Party (930,020) 	205,800	274,480
Group Homes	Bangor Portland	6 at each site 16 Clients/Year	Bureaus of Rehabilitation & Medical Services Contracted Programs	65,000	130,000	<ul style="list-style-type: none"> • Residents Contributions (64,500) 	43,500	87,000
Development and Coordination of Services to Head Injured Persons	Statewide	50 Clients	Bureau of Rehabilitation	22,500	30,000	<ul style="list-style-type: none"> • Title VII, Part A Federal Rehabilitation Act (55,500) 	-0-	-0-
Community-Based Services: <ul style="list-style-type: none"> • mental health • health services • IL skills training • cognitive re-training • housing • transportation • adult education • home modifications • adaptive/mobility equipment • peer/family counseling • recreation • pre-vocational training • vocational rehabilitation • advocacy 	Statewide	50 Clients @ \$6,000/Year	Services Contracted through: <ul style="list-style-type: none"> • community mental health centers • home health agencies • independent living programs • ME Head Injury Foundation • Regional Transportation Agencies • Sheltered Workshops • Rehabilitation Facilities • Schools 	225,000	300,000	<ul style="list-style-type: none"> • Bureau of Mental Health • Bureau of Mental Retardation • Bureau of Rehabilitation • DECS, Division of Adult Education • Medicaid/Medicare • ME Independent Living Center • HUD • Private Insurance (120,000) 	165,000	240,000
Personal Care Attendent/Advocate	Statewide	10 Clients	Bureau of Rehabilitation Contracted Service	140,250	187,500	<ul style="list-style-type: none"> • Home Based Care Act 	140,250	187,500
Professional Education	Statewide	150 Direct Service Providers	<ul style="list-style-type: none"> • Bureau of Rehabilitation • DMH/MR • Division of Special Education 	16,875	22,500	<ul style="list-style-type: none"> • Tuition/Fees • In-Service Training Funds (11,250) 	8,475	11,250
Public Education and Advocacy	Statewide	Head Injured Persons Families General Public	ME Head Injury Foundation	37,500	50,000	<ul style="list-style-type: none"> • Private (20,000) 	27,500	40,000
TOTAL				\$1,147,565	\$1,525,920	(\$1,201,270)	\$590,585	\$840,230

II. WHO ARE THE HEAD INJURED

A. Hospital Discharge Reports

Statistics provided by the Maine Health Information Center indicate that the median age of the head injury discharges in 1982 was 17 years of age -- in 1983 the median age was 22*. In both 1982 and 1983, 64 percent of the head injury discharges (statewide) were males; the ratio of male - female discharges across counties, however, varied substantially during both years.

Overall, the total number of the head injury discharges decreased from 1,540 in 1982 to 1,502 in 1983. Total number of hospital days, however, increased by 573 days (from 9,387 to 10,960). The average stay increased from 6.1 to 7.3 days.

The number of head injury patients who were hospitalized more than 20 days increased from 97 (1982) to 101 (1983). The 97 persons whose stay was greater than 20 days (6.3%) accounted for 51.4 percent of the total 1982 head injury hospital days. The 101 persons that were hospitalized for more than 20 days in 1983 (6.7%) accounted for 59.5 percent of the total head injury-related hospital days.

Disposition at discharge changed slightly in 1983 -- there was a slight increase in "other hospital" and "home health services" dispositions.

Additional statistics concerning the characteristics of the head injured population based on the data provided by the Maine Health Information Center are presented in the remainder of this section.

*Median: A Point on a scale such that half othe observations fall above it and half fall below.

1. Head Injury Discharges by County of Residence

As shown in Table II. A - 1, head injury discharges (statewide) decreased in 1983 by 38 (2.5%). Seven counties, however, experienced an increase in 1983 hospital discharges related to head injuries. They were: Franklin, Kennebec, Knox, Piscataquis, Sagadahoc, Washington and York Counties. (These same counties also had an increase in head injury discharges per 10,000 population.)

Table II. A - 1
1982 and 1983 Head Injury Discharges
By County of Residence

County of Residence	1980 Population*	Total Discharges		Discharges Per 10,000 Pop.	
		1982	1983	1982	1983
Androscoggin	99,657	136	117	13.65	11.74
Aroostook	91,331	140	138	15.33	15.11
Cumberland	215,789	261	218	12.10	10.10
Franklin	27,098	17	21	6.27	7.75
Hancock	41,781	91	79	21.78	18.91
Kennebec	109,889	115	147	10.47	13.38
Knox	32,941	39	45	11.84	13.66
Lincoln	25,691	62	47	24.13	18.29
Oxford	48,968	71	70	14.50	14.30
Penobscot	137,015	166	162	12.12	11.82
Piscataquis	17,634	25	37	14.18	20.98
Sagadahoc	28,795	48	75	16.67	26.05
Somerset	45,028	98	75	21.76	16.66
Waldo	28,414	54	38	19.01	13.37
Washington	34,963	66	67	18.88	19.16
York	139,666	151	166	10.81	11.89
Statewide	1,124,660	1,540	1,502	13.69	13.36

*Final Census Advance Reports

Source: Maine Health Information Center

2. Head Injury Discharges by Length of Hospital Stay

As apparent from Table II. A - 5, although there were 38 fewer head injury related discharges in 1983 than in 1982, the total hospital days increased from 9,387 to 10,960. The average length of hospital stay increased from 6.1 to 7.3 days and the longest stay increased from 213 to 417 days.

Table II. A - 5

1982 and 1983 Head Injury Discharges by Length of Hospital Stay

County of Residence	Total Discharges		Length of Stay					
	1982	1983	Total Days		Average		Range	
			1982	1983	1982	1983	1982	1983
Androscoggin	136	117	1,051	1,430	7.7	12.2	1-76	1-153
Aroostook	140	138	681	472	4.9	3.4	1-61	1-63
Cumberland	261	218	1,811	2,071	6.9	9.5	1-158	1-173
Franklin	17	21	47	126	2.8	6.0	5-83	1-30
Hancock	91	79	548	380	6.0	4.8	1-116	1-70
Kennebec	115	147	409	1,479	3.6	10.1	1-28	1-161
Knox	39	45	335	192	8.6	4.3	1-202	1-35
Lincoln	62	47	203	256	3.3	5.5	1-40	1-87
Oxford	71	70	382	519	5.4	7.4	1-81	1-71
Penobscot	166	162	1,304	1,280	7.9	7.9	1-176	1-296
Piscataquis	25	37	147	212	5.9	5.7	1-41	1-77
Sagadahoc	48	75	197	380	4.1	5.1	1-69	1-67
Somerset	98	75	596	390	6.1	5.2	1-213	1-46
Waldo	54	38	330	97	6.1	2.6	1-101	1-14
Washington	66	67	243	234	3.7	3.5	1-50	1-94
York	151	166	1,103	1,440	7.3	8.7	1-70	1-417
Statewide	1,540	1,502	9,387	10,960	6.1	7.3	1-213	1-417

In 1982, Franklin County had the lowest average length of stay (2.8 days) while Knox County had the highest average (8.6 days). In 1983, the lowest average was in Waldo County (2.6 days) and the highest average was in Androscoggin County (12.2 days).

B. Head Injuries on Maine's Highways

Data provided by Maine's Bureau of Safety (Department of Public Safety) indicate that in 1982 and 1983, 30,467 and 31,374 accidents, respectively, occurred on Maine's highways. In 1983, a slightly greater proportion of persons involved in highway accidents sustained bodily injury (48.5% compared to 48.3%).

In 1983 a total of 77,788 persons were involved in motor vehicle accidents in Maine. Eighteen percent of the individuals not using restraints sustained injuries and .3 percent were killed whereas 13.8 percent using restraints were injured and .1 percent were killed.

Motorcycle accident statistics provided by the Maine's Bureau of Safety show that the use of a helmet also reduces the risk of injury and death should an accident occur.

It cannot be determined from the statistics contained in this report what proportion of those injured sustained head injuries or injury to other areas.

In summary, Maine's statistics show that the use of restraints/safety devices reduces the risk of death and injury. Furthermore, head injuries comprise the largest proportion of injuries sustained in highway accidents.

C. Head Injuries at the Worksite

The Bureau of Labor Standards, Maine Department of Labor, in conjunction with the Maine Workers' Compensation Commission, annually collects and publishes work-related injury data. The Bureau compiles data on the nature and type of injury, source and severity, sex, age, county and industry. The Maine Head Injury Task Force obtained data for those workers who received head injuries in 1983.

1. Summary of Findings

In 1983, 928 workers received head injuries in work-related accidents:

- o Head lacerations were the most frequent injury and "struck by" or "struck against" metal items, hand tools (unpowered), vehicles and furniture were the most frequent cause of injury.
- o 76 percent of the injuries were nondisabling (requiring medical treatment only).
- o 22 percent of the injured workers were between 20-25 years of age. 58 percent were under the age of 35.
- o 80 percent were males.
- o 24.1 percent of the injuries occurred in Cumberland County.
- o Somerset and Franklin counties experienced the highest ratio of injuries to employed workers.

III. ASSESSMENT OF EXISTING SERVICES AND SERVICE NEEDS

A. Public Hearings Testimony

The Task Force conducted public hearings in Presque Isle, Bangor, Lewiston and Saco. More than 200 citizens attended these evening meetings. The participants included head injured persons, their families, health professionals, social service providers, educators and law enforcement officials. The variety of interest groups represented at the hearings reflects a broad public concern about head injury in Maine.

At each hearing, the Task Force heard similar testimony -- services for head injured persons are fragmented, underfunded and, to a large extent, non-existent. Following a standard format, participants were invited to share their experiences with hospital care, community services, special education, employment and financing services. This format enabled the Task Force to compare findings among regions, and, to highlight regional problems.

What follows is a summary of issues that consistently came up across the state, as well as issues particular to a specific region.

1. Hospital Care: Entering the System

With very few exceptions, families of head injured persons felt that support and information from hospital staff, particularly physicians, was generally inadequate. They found physicians inaccessible, and unwilling to answer questions. Families reported that they were given no information about the long term effects of a head injury, especially possible psychiatric problems and the slow re-learning process. Many sensed that physicians didn't have answers but were reluctant to admit what they didn't know. Others said that their head injuries went totally undiagnosed. A speaker at one hearing noted that even if medical professionals had given him information about his brother's head injury he probably wouldn't have remembered it because his immediate concern was for his brother's survival.

Poor discharge planning and no follow-up was the experience of many participants. Most said they left the hospital with no information about how to arrange for on-going services. The physician was identified as the key to post-hospital services; unless the physician orders home health services, third party payors won't reimburse these costs. Physicians and hospitals are so oriented toward in-patient care that they don't recognize the need for follow-up and out-patient services. Over

and over, participants reported how alone and "in the dark" they felt about being sent home with no support for making the transition into the community.

In northern Maine, geography and a lack of specialized services and equipment compounds the problem. Aroostook County doesn't have a fixed-based computerized tomography scanner. This means the area cannot attract the physician specialists needed to offer head injury treatment in the county. Head injured persons are hospitalized in Bangor or Portland, further complicating communication and coordination.

2. Community Services

Upon leaving the hospital, many participants quickly discovered that community-based services have narrow eligibility criteria and in many cases, they exclude someone with a head injury. A person may be accepted for services only to find that the staff has little or no experience working with the head injured. They also felt that many of these programs, like Vocational Rehabilitation, look for quick results; an unreasonable expectation when working with a head injured individual.

Again and again participants talked about the need for specialized head injury services in Maine. Many people described the frustration of trying to arrange reimbursement for out-of-state rehabilitation services for their head injured family member. Head injured persons reported a reluctance to participate in programs designed for mentally retarded and/or mentally ill persons. They also stated that a nursing home is not an appropriate setting for a head injured young adult. One young man likened nursing homes to lobster traps -- once you're in, you can't get out!

Residents in southern Maine expressed comparatively fewer complaints about the service system; in this part of the state it's more a case of regulatory barriers and less an unwillingness to work with the head injured. However, the lack of any post-hospital, residential programs is viewed as a problem in southern Maine as well as elsewhere.

3. Special Education Services

Problems in obtaining special education can be summed up in the words of one participant: "Money is the issue--they don't want to spend it." Others felt that school personnel needed more training in working with the head injured. Because schools lack experience and training in dealing with the head injured, some students are inappropriately placed.

Many parents find the Pupil Evaluation Team (PET) process intimidating. Some reported "getting nowhere" until the Advocates for the Developmentally Disabled or other parent advocates got involved.

Other parents found that their child was ineligible for special education; there were cases where recently injured students were graduated thus eliminating their right to any additional education services.

4. Employment

Going back to work after a head injury was described as difficult, and in many cases, impossible. Employers can't or won't accommodate head injured workers. Many said that employers refused to hire them because of the perceived risk of re-injury. Others reported being fired for behavior related to their head injuries.

At every hearing participants expressed frustration with the vocational rehabilitation system; they want to see VR do more to help head injured persons find and keep jobs.

5. Financing Services

Paying for services is a concern of both consumers and providers. Participants described how, in a third party reimbursement system, the label or diagnosis is the key to eligibility for benefits. Workers Compensation, Social Security Disability or insurance coverage for medical services all hinge on a physician's opinion.

Middle income families feel that the system discriminates against them--it seems that in order to obtain services you have to be either very poor or very rich.

Providers report that Medicaid reimbursement policies are geared toward short term, restorative care; head injury rehabilitation is a long-term and costly proposition. They feel that Medicaid is short sighted because an investment in rehabilitation up front could save on a lifetime of SSI/Medicaid benefits.

Many families would like to keep their head injured family member at home, but funding guidelines discourage this.

6. Prevention

Participants were vocal in their support of mandatory seat belt use. Other recommendations for reducing the number of head injuries in Maine were:

- . Mandatory helmet use for motorcycles and All Terrain Vehicles (ATVs)
- . Stiffer penalties for drunk driving

- . Require seat belts in school buses
- . Design safer automobiles
- . In lieu of mandatory seat belt legislation, adopt sanctions such as fines or no insurance reimbursement if involved in an accident and not using seat belt

B. Survey of Head Injured Individuals

In addition to using the Public Hearings as a means of assessing existing services and service needs of the head injured population, the Task Force conducted a mail survey of head injured persons in Maine. This section of the report presents the survey findings.

In September, 1984, the Task Force mailed out 369 surveys to head injured persons residing in the State of Maine. (A copy of the survey questionnaire and the cover letter may be found in Appendix III-1.) As of October 15, 1984, the deadline for returning the completed survey, 103 persons had completed and returned the survey questionnaire.

The primary purpose of the survey was to determine the extent to which the existing service system was addressing the needs of head injured persons. However, items pertaining to demographics were also included on the survey questionnaire in order that service needs could be assessed in relationship to the head injured survey respondent's characteristics.

The majority of the respondents are 33 years of age or younger (74%), living with spouse or parents (63%) and reported they do not require assistance with their personal care needs (70%).

Sixty-eight percent of the head injuries were related to motor vehicle accidents (including being hit by a car) and motorcycle accidents. Sixty percent of the injuries occurred between 1980 and the date of the survey (September 1984). As a result of the injury, 65 to 70 percent of the respondents reported memory loss, balance/walking and emotional impairments.

The majority of the respondents did not pursue any education (69%) or training (93%) after the injury. Whereas prior to the injury 51 percent of the respondents had full time employment, 51 percent were unemployed at the time of the survey (post-injury) and only 10 percent were employed.

Findings pertaining to existing services and the additional services needed are presented first, followed by the characteristics of the respondent group.

As is apparent from Table III. B - 5, the respondent group indicated that the services most needed by head injured persons are 1) vocational rehabilitation, 2) medical care; 3) individual mental health counseling; 4) education/training; and 5) neuropsychological testing.

Table III. B - 5
Reported Unmet Service Needs of Head Injured Persons

Service	Total Reported Need	No. Receiving Service	Unmet Need
Vocational Rehabilitation	66	20	46
Education/Training	40	7	33
Individual Mental Health Counseling	44	16	28
Recreational Therapy	31	5	26
Neuropsychological Testing	37	13	24
Independent Living	23	--	23
Occupational Therapy	41	19	22
Sheltered Employment	28	4	22
Physical Test/Therapy	35	14	21
Cognitive Retraining	25	7	18
Family Counseling	21	3	18
Speech/Language Therapy	31	15	16
Social Services	31	16	15
Nutrition Counseling	16	3	13
Hearing Test	19	7	12
Eye Test	26	15	11
Personal Care Assistant	11	--	11
Respite Care	11	--	11
Respiratory Therapy	10	2	8
Home Health Nursing	10	2	8
Medical Care	45	38	7

C. Survey of Service Providers

The Task Force conducted a survey of state and community-based health and social services in September, 1984. The purpose of the survey was to obtain data on the number and characteristics of head injured people in care and the kinds of services they receive. This section of the report contains a summary of the survey results.

1. Findings and Summary

The survey identified 152 head injured people who were receiving services.

The following is a summary of the findings:

- . only 16 percent (49) of the service providers surveyed served head injured clients on July 31, 1984.
- . 40 percent (61) of the head injured clients were receiving services in a type of residential facility (i.e. mental health institution, nursing home).
- . 43 percent were between 20-29 years of age. 64 percent were between 20-39 years of age. VR, MR services and hospital rehabilitation units served the very young, under twenty head injured clients, while nursing homes served the older, over 40 head injured clients.
- . 80 percent were male.
- . 50 percent were injured between 1980-1984. Eighty-six percent (86%) were injured between 1970-1984.
- . over 50 percent received nursing, physical therapy and social work services. Nearly half received occupational therapy and psychological counseling.

IV A COMPREHENSIVE HEAD INJURY SERVICE SYSTEM FOR MAINE

The optimal system of care is one which meets the individual's needs. Because the effects of head injury vary from person to person, no one model of service will meet the needs of all Maine's head injured citizens. Therefore, the Task Force recommends a continuum of services that would offer new, specialized head injury services at one level, and, rely on existing community-based programs at other levels. Of paramount importance is a sufficiently long continuum of care; the system must be flexible enough to accommodate the changing needs of head injured individuals.

Overall, goals of a comprehensive system of services are:

- . To reduce the incidence of head injury.
- . To maximize the recovery of the head injured individual
- . To minimize the financial and emotional impact on families of head injured persons.
- . To utilize resources cost-effectively.

A. Prevention and Education

1. Findings and Recommendations

Because there is rarely a full and complete recovery from a serious head injury, prevention must be an essential component of a head injury service system. Also, we know that many head injuries -- especially those caused by motor vehicle accidents -- are preventable.

Seat Belts

The Task Force supports mandatory seatbelt legislation.

Drivers Education and Licensing

The Task Force recommends that defensive driving be included in all driver's education courses.

The Task Force also recommends that persons who are head injured have a vision test before their drivers licenses can be renewed.

Drinking and Driving

The relationship between drunk driving and care accidents is well established. The Task Force supports any legislative initiatives to further penalize and rehabilitate drunk drivers.

Public and Professional Education

The Task Force supports funding for the Maine Head Injury Foundation to take the lead in public education. The Foundation is the logical organization to carry on public awareness activity over a sustained period of time. It's members are energetic and knowledgeable. They are capable of understanding the consequences of head injury and communicating their experience to the public.

The Foundation should work in conjunction with such groups as the Maine Highway Safety Council, Mothers Against Drunk Drivers and the Maine Medical Association to raise public and professional awareness of the causes and consequences of head injury. Educational activities might include public service announcements, public forums, in-service programs for health professionals and publication of a resource guide for head injured persons and their families.

B. Trauma and Hospital Care

1. Findings

The public hearings were the principal source of information about the treatment of head injuries in Maine hospitals. There were few comments critical of the adequacy of medical treatment, either at the public hearings or in the survey of head injured individuals. The Task Force, therefore, did not systematically evaluate the quality of medical care provided head injured persons.

Most of the concern centered on two issues: 1) lack of information about the consequences of head injury; 2) and the perceived inadequacy of discharge planning.

2. Recommendations

The Task Force recommends:

- . Head injured persons be transported to hospitals having 24 hour neurosurgical coverage
- . Hospital social workers receive additional training in discharge and follow up planning for head injured persons
- . Maine Head Injury Foundation develop a network for providing information and support to families of newly-head injured persons.

C. Brain Injury Unit

1. Findings

Recent technological advances in medicine enable trauma care physicians to save the lives of many brain injured individuals who formerly would not have survived. This progress is not without its price, for many of the survivors leave the hospital with permanent physical and mental disabilities. And unfortunately, the level of care available in the community doesn't begin to match the quality of services offered in the hospital setting.

Maine needs at least 12 beds in a skilled nursing facility (SNF) where brain injured patients could receive up to 18 months of post-hospital, residential care. The rationale for a single 12 bed brain injury unit is two-fold: 1) Maine hospital discharge data indicates that of the 100 people who were hospitalized with a head injury for more than three weeks, 11 were discharged to a nursing facility; and 2) the National Commission on Accreditation of Rehabilitation Facilities guidelines suggest that a minimum of ten dedicated beds are necessary to maintain a viable brain injury rehabilitation program.

The following range of services shall be available:

- . Attending Physician and Special Medical Consultations
- . Twenty four hour Skilled Nursing Care and Physician Coverage
- . Rehabilitation Nursing Services
- . Physical Therapy
- . Occupational Therapy
- . Speech and Language Therapy
- . Audiological and Visual Screenings
- . Psychological Counseling for Patient and Family
- . Neuropsychological Testing
- . Social, Recreational and Spiritual Services
- . Vocational Rehabilitation Services
- . Cognitive Re-Training
- . Adaptive/Mobility Equipment Consultation
- . Driver Evaluation/Education
- . Educational Services
- . Therapeutic Dietary Services
- . Diagnostic Radiological and Laboratory Services
- . Orthotic and Prosthetic Services
- . Pharmaceutical Services
- . Respiratory Therapy Consultations and Treatments
- . Staff Education

Assessment, coordinated program planning, and direct services on an intensive, regular, and continuing basis should be provided by a core team of allied health professionals with training and experience in brain injury rehabilitation. The core team should be specifically designated to serve brain injured individuals on a fulltime, not a contractual, basis.

There should be a written plan of followup care. The brain injury unit should provide for its own followup care when this is appropriate for those people who remain in its service area. Arrangements to facilitate followup care should be made for those who will leave the unit's geographic service area.

Criteria for admission to the brain injury unit will include:

- . Traumatic or non-traumatic brain injury
- . Requires comprehensive inpatient rehabilitation services to optimize potential for recovery
- . Age between adolescence to adulthood
- . Acceptance by admissions committee
- . Medically stable

The unit is not intended to function as a stroke rehabilitation program, although some younger persons with cerebral vascular accident or similar disabilities could be served.

D. Community-Based Services

1. Findings

The experience of other disability groups has demonstrated that the community is a more cost effective and appropriate site for many of the services formerly offered in institutional settings. This is also true for persons disabled by a head injury who may show continued improvement long after they have been discharged from the hospital.

Today in Maine there is a statewide network of community-based programs providing health, mental health, vocational, recreational, social, independent living, transportation and educational services. Very few of these agencies are serving the head injured and the reason is a simple one -- no money to train staff or to develop programs for this population. Another barrier is that categorical funding for community programs results in fairly narrow eligibility criteria and all too often the head injured simply don't "fit".

The Task Force recommends that, where feasible, services for head injured persons build on the foundation of existing community services. Program and funding guideline's however, must be flexible in order to accommodate the varied needs of the head injured individual.

The matrix on the following page outlines a community-based service system.

Table IV.D.1

Components for a Head Injured Person Community-Based Service System

Service Component	Location	Number of Beds/ Clients Served/Yr	Provider	Estimated Cost		Existing Sources Of Funds	Additional State Funds for Next Biennium	
				1985-86	1986-87		1985-86	1986-87
Group Homes	Bangor Portland	6 at each site 16 Clients/Year	Bureau of Rehabilitation & Medical Services Contracted Programs	65,000	130,000	• Residents Contributions (64,500)	43,500	87,000
Development and Coordination of Services to Head Injured Persons	Statewide	50 Clients	Bureau of Rehabilitation	22,500	30,000	• Title VII, Part A Federal Rehabilitation Act (55,500)	-0-	-0-
Community-Based Services: • mental health • health services • IL skills training • cognitive re-training • housing • transportation • adult education • home modifications • adaptive/mobility equipment • peer/family counseling • recreation • pre-vocational training • vocational rehabilitation • advocacy	Statewide	50 Clients @ \$6,000/Year	Services Contracted through: • community mental health centers • home health agencies • independent living programs • ME Head Injury Foundation • Regional Transportation Agencies • Sheltered Workshops • Rehabilitation Facilities • Schools	225,000	300,000	• Bureau of Mental Health • Bureau of Mental Retardation • Bureau of Rehabilitation • DECS, Division of Adult Education • Medicaid/Medicare • ME Independent Living Center • HUD • Private Insurance (120,000)	165,000	240,000
Personal Care Attendant/Advocate	Statewide	10 Clients	Bureau of Rehabilitation Contracted Service	140,250	187,500	• Home Based Care Act	140,250	187,500
Professional Education	Statewide	150 Direct Service Providers	• Bureau of Rehabilitation • DMH/MR • Division of Special Education	16,875	22,500	• Tuition/Fees • In-Service Training Funds (11,250)	8,475	11,250
Public Education and Advocacy	Statewide	Head Injured Persons Families General Public	ME Head Injury Foundation	37,500	50,000	• Private (20,000)	27,500	40,000
TOTAL				\$507,125	\$720,000	(\$271,250)	\$384,725	\$565,750



The University of Southern Maine
A UNIT OF THE UNIVERSITY OF MAINE

