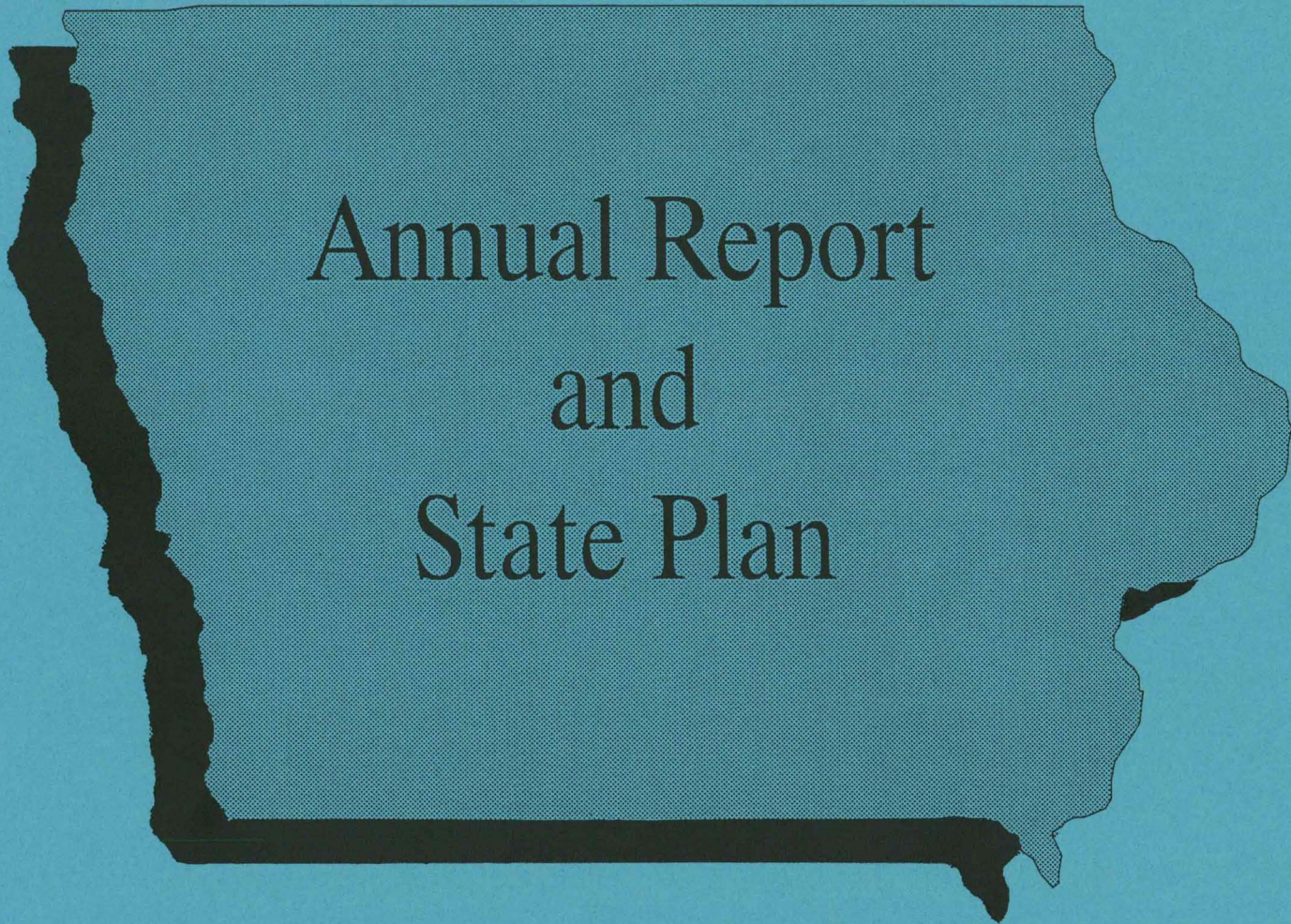


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# Iowa Advisory Council On Head Injury

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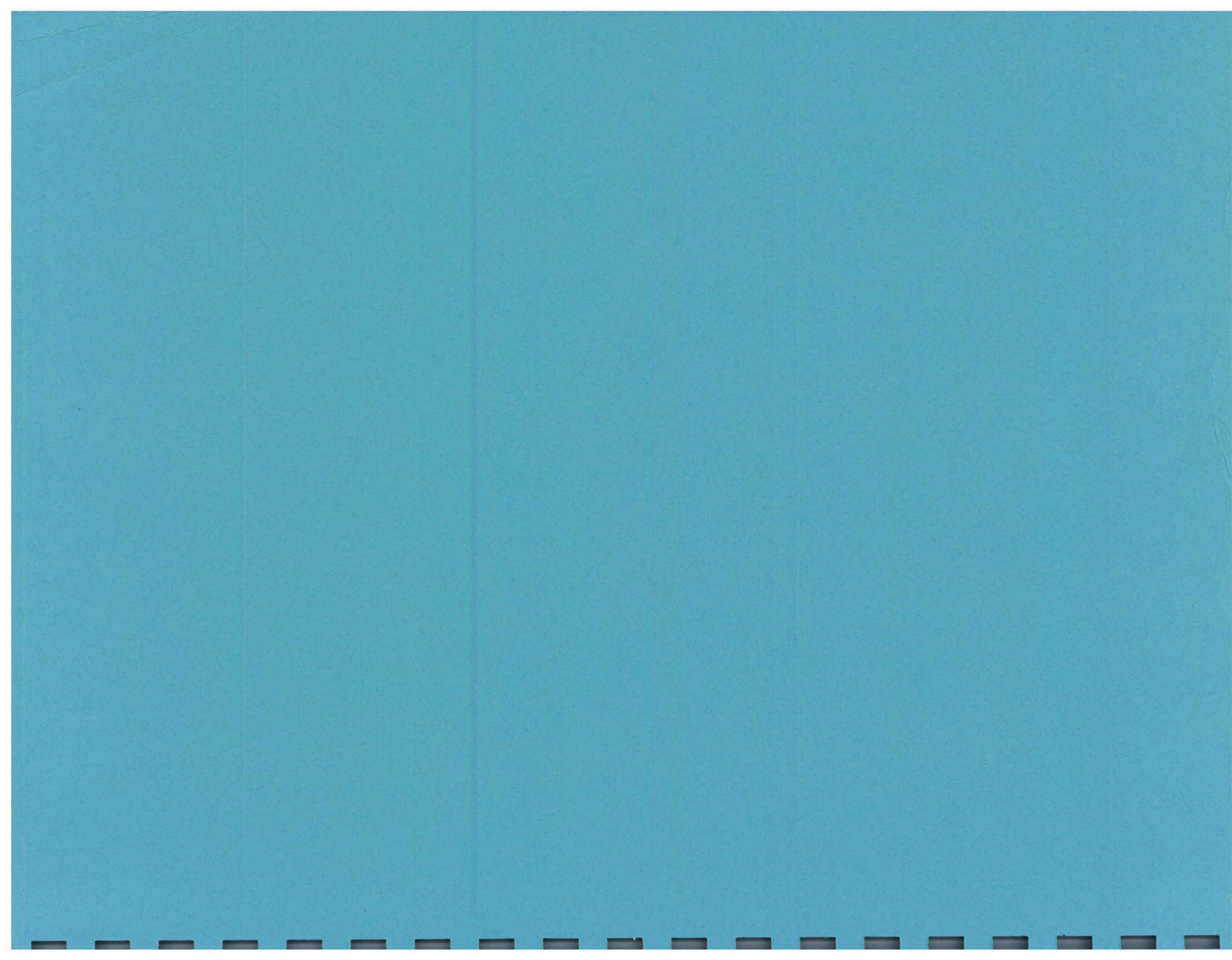
Annual Report  
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**IOWA ADVISORY COUNCIL**

**ON HEAD INJURIES**

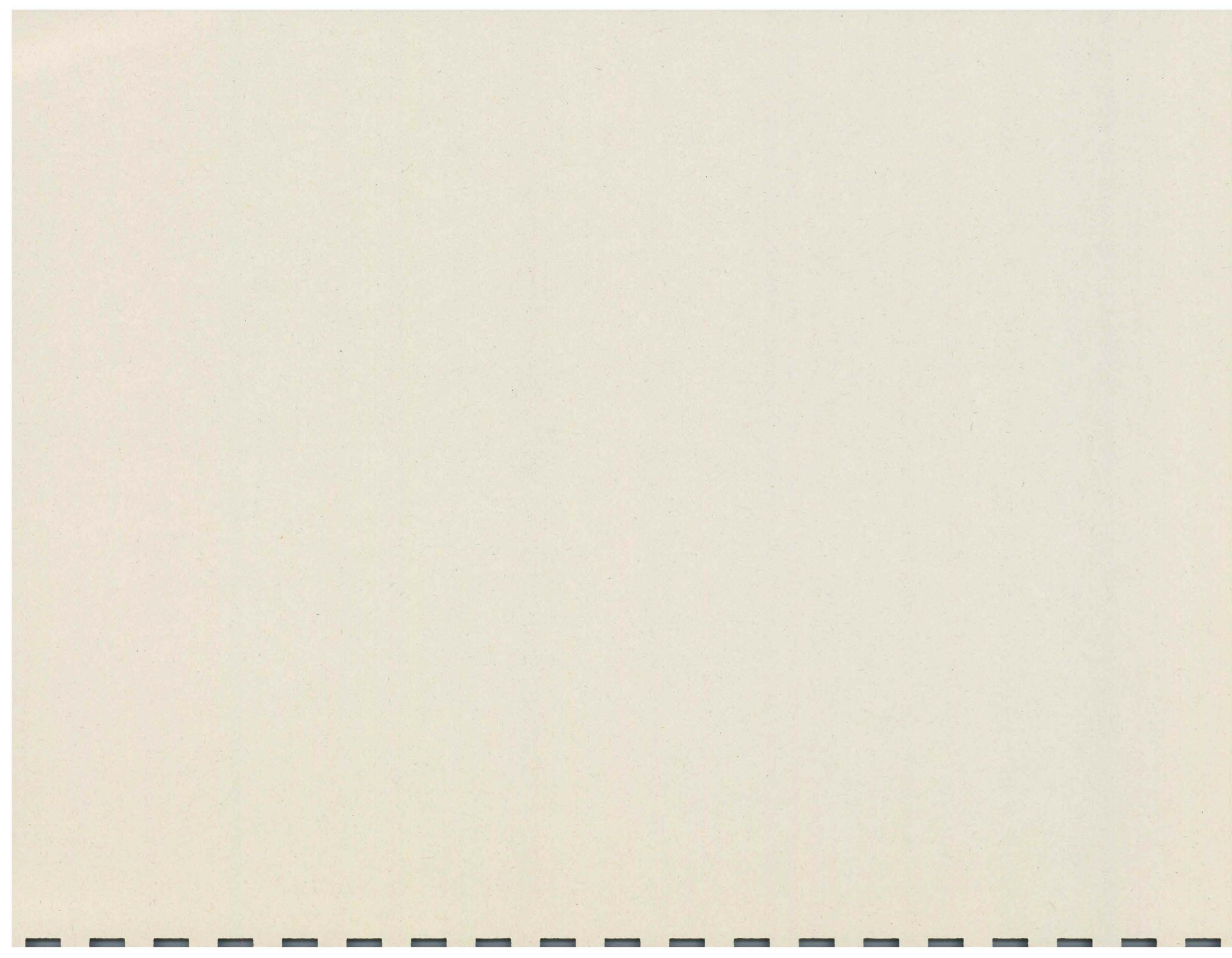
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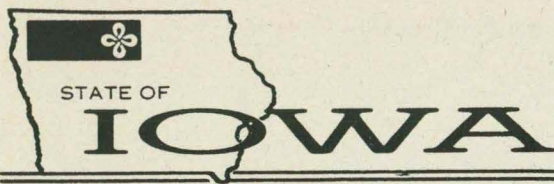
**STATE PLAN**

**1994**

**FEBRUARY 1995**







TERRY E. BRANSTAD, GOVERNOR

DEPARTMENT OF PUBLIC HEALTH  
CHRISTOPHER G. ATCHISON, DIRECTOR

February 10, 1995

The Honorable Terry E. Branstad  
Members of the General Assembly  
State Capitol Building  
Des Moines IA 50319

Dear Governor Branstad and Members of the Assembly:

On behalf of the Iowa Advisory Council on Head Injuries it is my pleasure to forward to you the Annual Report as required by Iowa Code summarizing the activities of the Council for the past year.

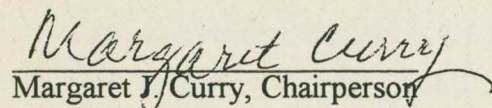
As Chair of the Advisory Council, I must tell each of you, there is a great sense of frustration throughout the state from survivors of brain injury, family members and professionals who are trying to put lives back together after brain injury. Through passage of the Category Bill in 1988, Senate File 302, brain injury is to be recognized as a distinct disability, yet we realize more each day that services in Iowa are fragmented, not cost effective, inappropriate or not available at all.

The Council will strive to create a greater awareness of brain injury and will continue to educate and advocate for implementation of all legislative issues for prevention of brain injury. These measures have proven to save many thousands of dollars to the state and relieve much of the pain and anguish that takes place in the lives of survivors of brain injury and their families. We share the vision of equality of services to persons with all disabilities and will continue working through the System Change Project and other advocacy groups toward that end. We will be looking to each of you to fulfill your moral and fiscal responsibility to people with disabilities and the State of Iowa.

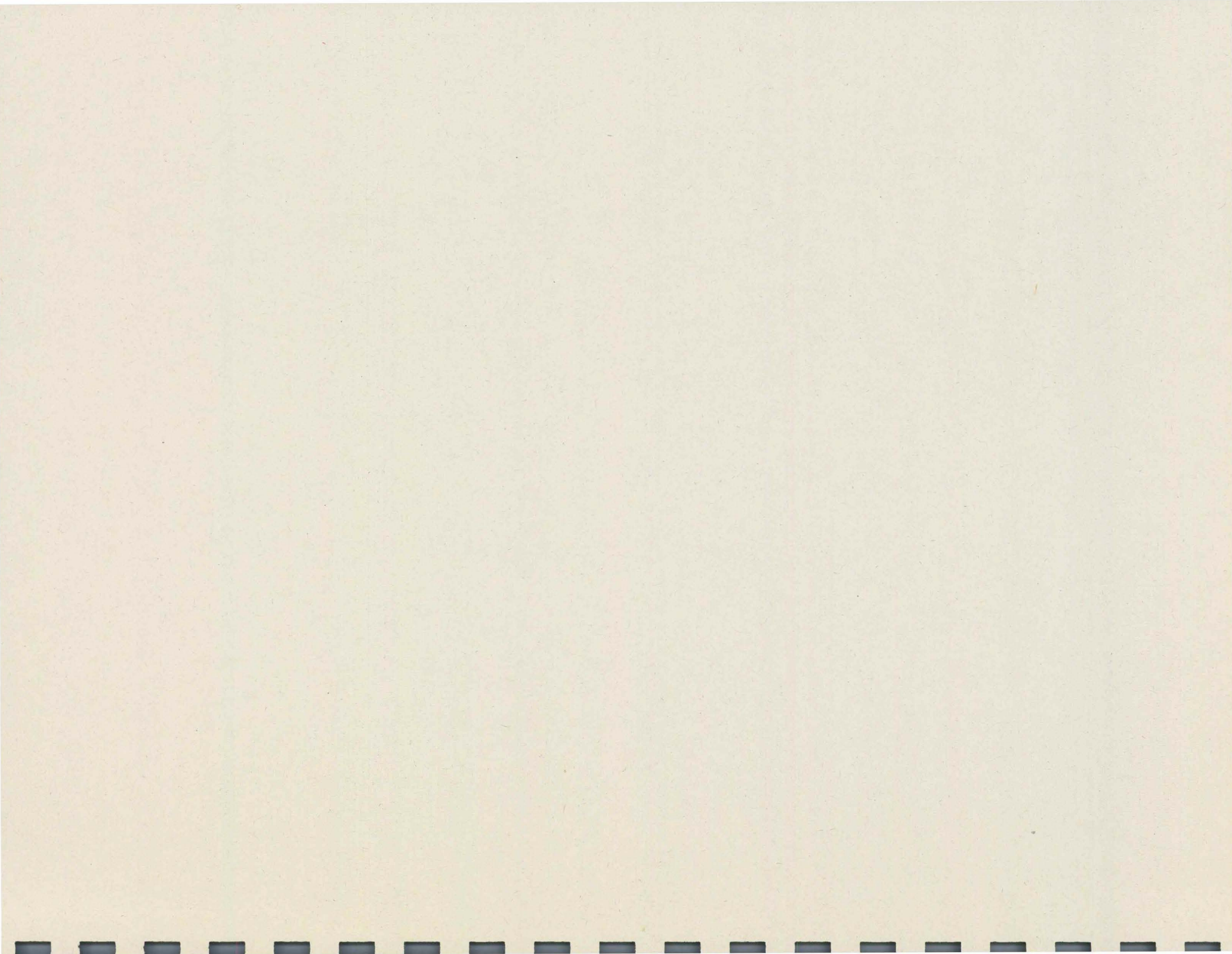
Thank you for your continued support of persons with brain injury and we look forward to working with you as we strive to meet the many needs of Iowa's most valuable resources - its citizens.

A full report from the Service and Prevention Task Force are included. Please review them carefully.

Respectfully submitted,

  
Margaret J. Curry, Chairperson







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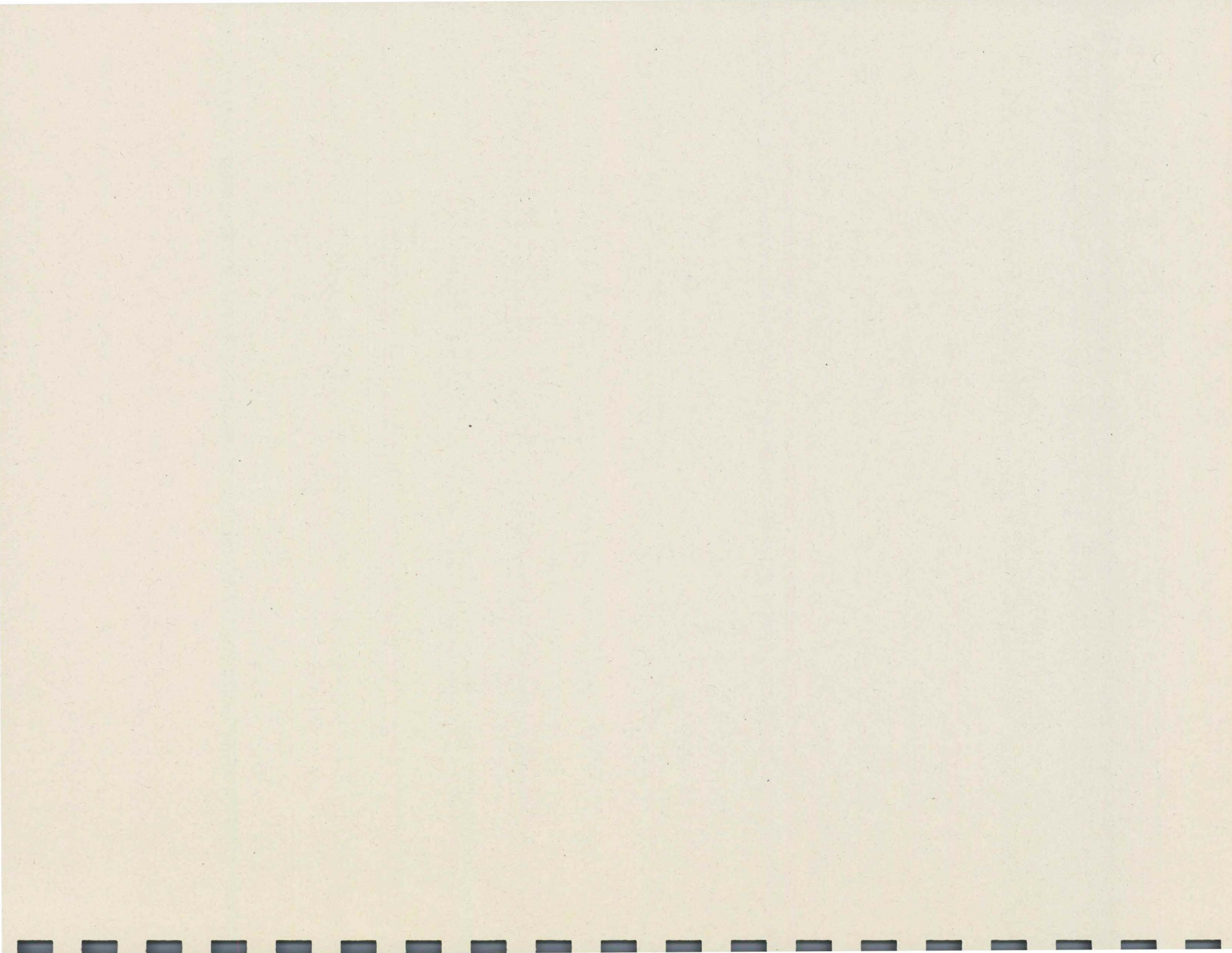
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## INTRODUCTION

The lack of funding options or a comprehensive service delivery system that appropriately addresses the unique needs of survivors of head injury propelled Iowans to action. In response to these needs, the Iowa Legislature passed a bill establishing the Governor's Advisory Council on Head Injuries in the spring of 1989. The Council was administratively assigned to the Division of Persons with Disabilities within the Department of Human Rights until the legislative session in 1992 when it was transferred to the Bureau of Disabilities and Injury Prevention within the Department of Public Health.

### MISSION STATEMENT FOR IOWA ADVISORY COUNCIL ON HEAD INJURY

#### *THE MISSION OF THE COUNCIL IS TO:*

- ***STUDY THE NEEDS OF INDIVIDUALS WITH HEAD INJURY AND THEIR FAMILIES***
- ***PROMOTE AND IMPLEMENT INJURY PREVENTION STRATEGIES***
- ***MAKE RECOMMENDATIONS REGARDING THE PLANNING, DEVELOPMENT, AND ADMINISTRATION OF A COMPREHENSIVE STATEWIDE SERVICE DELIVERY SYSTEM***

The Council meets quarterly to make recommendations regarding funding, legislative initiatives, prevention, the appropriate programs that utilize professionals trained specifically in brain injury, rehabilitation, long term care, and community support services. Two task forces were formed to examine these issues, one focused on prevention and the other service provision. The subcommittees report to the complete Council. The task forces may meet more frequently than quarterly depending on their progress in meeting their objectives.

This report will provide an update on the Council's progress toward attainment of these goals and objectives. The state plan includes action plans and objectives based on annual goals. This enables the Council to plan and evaluate progress based on immediate needs, while maintaining insight into the future challenges.



## OVERVIEW

Traumatic brain injury (TBI) is referred to as the "Silent Epidemic" with approximately one million injuries occurring annually nationwide. "Head injury" or "traumatic brain injury" is damage or sudden insult to the brain or its coverings, not of a degenerative or congenital nature. This insult or damage can produce an altered state of consciousness that may result in personality and intellectual changes, as well as physical, behavioral, or emotional function. Since no two injuries are alike, a person may exhibit one or all of these conditions. The consequences of brain injury and its disabling effects are socially, educationally, medically, and economically devastating to individuals, families, and our communities. Consider the following:

- every person has a 1 in 10 chance of suffering a significant head injury;
- nationally an estimated 70,000 people a year incur moderate-to-severe head injuries;
- brain injury is the leading cause of death for Americans under the age of 34;
- an estimated 8,000 Iowans sustain a head injury annually, with 1,700 of those suffering moderate to severe disabilities;
- children and young adults are disproportionately affected with the majority of victims being male between the ages of 15-24;
- in Iowa, over half of the bicycle injuries occurred between the ages of 5 and 14;
- approximately 2,311 school-aged children in Iowa sustained traumatic head injuries; 656 of these cases were serious enough to require hospitalizations;
- motor vehicle crashes are the leading cause of TBI nationwide;
- the cost for one person with a severe head injury for acute care is estimated to \$435,950 and the annual lifetime care costs between \$32,250 - \$63,050 according to American Re-Insurance Company;
- persons with TBI are currently being held in a more restrictive environment receiving inappropriate levels of care due to a lack of community-based services and supports;
- survivors of bicycle head injuries have only a 33 percent chance of escaping a permanent disability.

Medical and technological advances have resulted in greater rates of survival for persons sustaining traumatic head injury. **The result is an emerging population of young, dissabled survivors.** The increased survival rate has placed a burden on current rehabilitation services, long term care, supervised residential living, vocational rehabilitation, supported employment, and community support programs.

As concerned citizens, we need to address the present issues and identify further challenges to assure survivors of TBI and their families appropriate, accessible, affordable and available services.



## DEFINITION

Traumatic head injury is a sudden insult to the brain, not of a degenerative or congenital nature, caused by an external physical force or agent, that may produce a diminished or altered state of consciousness, which may result in the impairment or alteration of the following: cognition, personality, physical, behavioral, or emotional function. These impairments may be either temporary or permanent and cause partial or total disability.

Medically there are two primary types of head injury: traumatic and non-traumatic. A traumatic brain injury can be categorized as open or closed head injury. An "open head injury" is caused when an object forcefully penetrates the skull and brain, thereby damaging the brain. A "closed head injury" refers to the damage to the brain that is caused without penetration of the brain. Non-traumatic causes of brain injury involves chemical agents, loss of oxygen to the brain, and brain pathology.

### Iowa Code 135.22

"brain injury" means clinically evident brain damage or spinal cord injury resulting from trauma or anoxia which temporarily or permanently impairs a person's physical or cognitive functions.

During acceleration/deceleration events, such as motor vehicle crashes, the brain is tossed and rotated within the skull. Because the brain is encased within a rough, bony, rigid skull; strong impact may cause a ripple effect throughout the gelatin-like brain, causing the brain to twist and tear. Bleeding within and around the brain tissue as well as swelling leads to increased intracranial pressure that leads to additional brain damage. Localized damage may also occur with bruising or tearing of brain tissue.

Persons with a head injury commonly experience deficits in one or all the following categories. The effects of head injury vary greatly, depending on the nature and severity of the injury:

- **Cognitive impairments:** memory deficits (long or short term), self awareness, communication, spatial relations and perception, coordination, conceptual and constructional skills, attention and concentration, reading, writing, sequencing or judgment, problem solving, planning and decision making, thinking and reasoning, and decreased capacity for abstraction.
- **Physical impairments:** vision, hearing, speech and other sensory impairments, balance, ataxia, strength and equilibrium, spasticity of muscles, range of motion, coordination, headaches, spatial orientation, paralysis on one or both sides and seizure disorders. Many persons with head injuries appear to be recovered physically, but may experience problems with fine motor control.
- **Social/behavioral impairments:** self esteem, awareness of social rules and roles, impulsivity, confabulation, impatience, appearance and grooming, family relationships, lethargy, emotional lability, age-appropriate behavior, lack of motivation, depression, sexual dysfunction and denial.



## **COUNCIL TASK FORCE REPORTS**

### **Prevention**

The Prevention Task Force of the Advisory Council on Head Injuries is recommitting its actions and efforts to establish a bicycle helmet and universal motorcycle helmet law. Council members attended a Bicycle and Motorcycle Head Injury Prevention Symposium in December in Iowa City. From this symposium the Iowa Head Injury Association formed the Iowa Helmet Education Committee. Many state-wide organizations are supporting these legislative initiatives such as the University of Iowa Injury Prevention Center, Blue Cross Blue Shield, Principal Financial Group, Disability Policy Council, American Academy of Emergency Physicians, Critical Care Nurses, Iowa Nurses Association, American Academy of Pediatrics, Iowa Methodist Medical Center, SAFE KIDS, Parent/Teacher Organization, Junior League, System Change Project, and Iowa Departments of Public Safety, Transportation, Human Services, and Public Health. There are numerous other organizations and individuals who are committed to the prevention and reduction of head injuries and fatalities. We are supporting this cause by recommending helmet laws, educational campaigns, and helmet rebate/coupon programs.

The Council enlisted support from key legislators and the Department of Public Health legislative liaison to help assist with strategic planning for the 1995 legislative session.

We are continuing to work with the registry to improve the quality of data and to utilize the data in other needed areas of prevention. We are advocating for coordination between existing data systems within the Department of Public Health such as Emergency Medical Services and Hospital Discharge Information and death certificate data.

### **Service Provision**

The Service Provision Task Force has had two primary and inter-related projects this year. The first has been to research and analyze information about the extent and capacity of statewide TBI services and costs associated with those services. This information was used to assist the Iowa Legislature in its decision to support legislation directing the development and implementation of a Home and Community-Based Medicaid Waiver for persons with brain injury. Members of the Council attended the Governor's signing of this major piece of legislation for the head injury community.

The second significant accomplishment was in collaboration with the Iowa Department of Public Health and the University of Iowa, Department of Preventive Medicine. This collaboration has resulted in the design of a comprehensive survey which will assess the scope and cost of brain injury services across the state. This survey is scheduled to be mailed in early 1995. Analysis will continue through the spring and the Council plans on publishing results in the summer of 1995.



## PREVENTION COMPONENT

Based on injury statistics, it is apparent that the incidence of head injury can be greatly reduced through prevention activities. Injuries have traditionally been perceived as unavoidable "accidents," rather than a health problem. Most unintentional injuries, however, are not "accidents," that is, random acts of fate that result in injury and death. Rather, the majority of the injuries are controllable and preventable, and in light of the risks taken, predictable. "Injuries" are the leading cause of death and disability in children and young adults and cause the loss of more working years than all forms of cancer and heart disease combined.

Three general strategies are available to prevent injury:

1. Education - Persuade persons at increased risk to alter their behavior.
2. Legislative - Require individual behavior change by law or administrative rule.
3. Engineering - Provide automatic protection by product and environment design.

### Overview:

If Iowa had a universal motorcycle helmet law in 1994, 9 lives would have been saved, 79 severe injuries prevented with economic savings of over \$10 million for our state. These data are according to the National Highway Traffic Safety Administration HELMETUSE report based on Iowa statistics. Without the passage of the motorcycle helmet law, we can establish a high likelihood that within the next two years, a 14 year old from Dubuque Hemstead, a 16 year old from Sioux City Heelan and an 18 year old graduate of Des Moines Dowling will each receive a catastrophic brain injury that will either take their life or at best, cause them to be severely disabled. As if we were in some "time warp," we have the ability to alter the course of history for these young people who will be facing either disability or death. If we could see a universal motorcycle helmet law, these same young people will marry, gain employment and have their own children. Without a helmet law in Iowa, all these things will be lost, not only to these young people, but also to the people that love them.

Many Iowa citizens and state-wide organizations are taking an active role in seeking to enact legislation that would reduce the numbers of traumatic brain injuries. **Members of the Council are committed to the reduction of traumatic brain injuries through proven prevention efforts, such as bicyclists who wear helmets reduce their chance for a head injury by 85 percent and a non-helmeted motorcyclist is three times more likely to sustain a head injury.**

**HELP IOWA JOIN THE REST OF THE NATION IN REQUIRING CYCLE HELMETS.**



**Helmet Usage-Motorcycles:** Motorcycles are associated with the highest mortality rates of all forms of motor transportation. Per passenger mile, mortality is 16 times greater than for cars.

The most successful strategy for reducing mortality and brain injury has been the passage of mandatory helmet laws. Among states having passed legislation, helmet use typically increased from 50 percent to 100 percent of motorcyclists wearing helmets. *The National Highway Safety Administration estimates Iowa would have saved 114 lives and \$123.2 million from 1984 to 1992 with 100 percent motorcycle helmet use.* Scientific studies have shown that the increase in helmet use is followed by a reduction in deaths by as much as 30 percent. In Iowa, a 35 percent reduction in the number of fatalities (per 10,000) motorcycle registrations was seen when a mandatory helmet law was in effect (from September 1975 until June 1976) as compared to before the passage of this law. After the repeal of the law, the number of fatalities was very similar to before this mandatory helmet use.

While the death and disability of Iowa motorcyclists have risen, motorcycle related deaths in Nebraska are down by 60 percent since that state enacted a law requiring motorcyclists to wear helmets. In the six years before the Nebraska law took effect, an average of 25 motorcycle riders were killed in traffic crashes. The average since the law took effect has been 10.

In addition to the reduction in risk of death among helmeted riders, they are also less likely to sustain a head injury, have a shorter stay in an intensive care unit when injured, and have a less frequent need for rehabilitation. One of the most compelling arguments, particularly in the era of limited medical resources and emphasis on cost containment, is that those not wearing a helmet incur an average of \$5,000 more per injured persons in acute medical expenses. The acute care costs are 40 percent greater in those who do not wear a helmet. The \$5,000 difference in cost is a substantial underestimation of the total cost of medical care since this difference only includes acute care cost and not rehabilitation and re-admission for treatment of delayed problems both of which are more frequent among unhelmeted motorcyclists.

In a recent study, 44 percent of medical costs for unhelmeted motorcyclists were paid by the tax payer as compared to 32 percent for the helmeted group. Thus, the medical costs are higher for unhelmeted riders and tax payers pay a larger portion of this compared to helmeted riders. There are few reasons why the findings of previous scientific studies would not apply to Iowa.

Some may think that wearing helmets increases the likelihood of sustaining a neck injury, thereby disabling the motorcyclist. In a recent Iowa study, this statement was refuted. Helmeted riders are just as likely to sustain a cervical spine injury as those without helmets.

Other states whose laws were repealed and then later reinstated have noticed a significant number of lives saved. Iowa is but one of three states, along with Colorado and Illinois, which do not have some type of mandatory helmet law. The federal government requires states to have helmet laws or to spend federal dollars on safety related programs. By not having a helmet law, Iowa is spending \$1.9 million on those safety programs in FY 1995. That figure will rise to \$4 million for FY 1996. The funds are provided to the Governor's Traffic Safety Bureau. If Iowa had a helmet law, the funds would go to the Road Use Tax Fund.



**Helmet Usage - Bicycles:** The goal of bicycle education and legislation programs is to increase the use of bicycle helmets, thus reducing the number of head injuries and deaths caused by bicycle crashes. In 70 -80 percent of bike related deaths, the primary or contributing cause of death is head injury.

Bicycling is a popular activity in the U.S. Approximately 80- 90 percent of all children own a bicycle by the time they are in the second grade. In 1993, over one-half of the 229 bicycle injuries occurred to Iowa children between the ages of 5 and 14. **Bicycle helmets reduce the risks of head injury by 85 percent** as shown in a recent study in Seattle. Increasingly states and local communities are developing laws that are making helmet use mandatory. Iowa has the opportunity to be among the leaders in the nation for establishing an effective and inexpensive prevention strategy to reduce head injury.

Helmets are not required for mopeds, which only recently have come into widespread use and are used most by adolescents. Bicyclists, as well as moped operators, benefit from protective helmets. All terrain vehicles (ATV) have recently become popular for recreational and agricultural use. Shortly after the introduction, the Consumer Product Safety Commission began receiving reports of large numbers of ATV injuries and an alarming number of deaths, most of which were caused by massive brain and spinal cord injuries. The number of reported ATV injuries may be an underestimation of the true figures. There is not an ICD-9 code that exists exclusively for ATV's, so they cannot be identified in hospital discharge data or death certificates. There are no regulations in Iowa for ATV's, except that they are prohibited on public roads. Providing ATV users with extensive instructional material has not been and will never be a solution to ATV's, which have serious design problems. The popularity of ATV's among young children has greatly compounded the consequences of using these inherently dangerous vehicles.

**Falls:** Falls are the most common cause of reported traumatic brain injury to people in Iowa. The circumstances under which falls occur vary widely, making it difficult to recommend broadly applicable prevention strategies. The distribution of falls tends to be bimodal in nature, occurring to the very young and the very old. Among the most frequently specified circumstances of fatal falls are falls on stairs, out of buildings, and from ladders and scaffolds.

The first step to identify potential prevention measures for falls is to gain a more detailed insight into the circumstances of their occurrence. To date, no comprehensive prevention efforts outside of institutional settings have been identified within Iowa to deal with the problem of injuries resulting from falls.

**Motor Vehicles:** In 1993, the leading cause of Iowans being hospitalized was from traumatic head injuries related to motor vehicles. Motor vehicle crashes are the second leading cause of all reported traumatic brain injury in Iowa. Motor vehicular crashes include automobiles, motorcycles, other motorized vehicles, and automobile/pedestrian collisions. The focus of most prevention activities have been on the causes of this category of injuries.

The U.S. Department of Transportation reports that in fatal and nonfatal motor vehicle crashes the severity of injury to the head is greater than injury to any other anatomic region. Furthermore, clinical studies show that when multiple injuries are present, the brain injury is the major determining factor in predicting the patient's prognosis. Clearly, any measure that prevents motor vehicle crashes will also reduce the incidence of brain injuries. Measures designed to reduce injury severity will also play an important role in preventing and limiting brain damage.



**Occupant Safety:** Motor vehicle occupant protection is one approach to injury control. Safety belts and air bags have been shown to be effective in saving lives and preventing injuries.

Lap-shoulder belts reduce the risk of death in a motor vehicle crash by about half. They provide protection for the head in low speed crashes by preventing contact with hard or lacerating surfaces. They also provide protection for back-seat passengers. Of particular importance is the role of the safety belt in preventing ejection of occupants in roll-over crashes. **Ejection is associated with high mortality rates: 25 times higher than for occupants not thrown from vehicles. However, safety belts need to be worn properly to provide maximum protection.**

When used alone, however, safety belts do not provide maximum protection for the head. In high speed crashes, spinal cord injuries, acceleration/deceleration brain injuries and impact brain injuries may occur, even when safety belts are properly worn. Air bags play an important role in preventing head injuries in head-on crashes.

Iowa law requires safety belts. However, the law only applies to passengers in the front seat of automobiles. Iowa also has a mandatory child restraining law for children under six. Children six years of age and older are not covered by safety restraint legislation unless they are a front seat passenger. For younger children, this is inadequate restraint legislation without the requirement of proper use of child safety seats.

**Teens and Young Adults-A Population At Risk:** Teenagers represent the highest age group for injury and death in motor vehicle crashes; and statistics in Iowa support this. A sharp increase is noted at age 15, which may relate to the age when teenagers start driving. The peak age for motorcycle fatalities is slightly higher (25-34 years old) than for automobiles. Consider the following:

- In the 15-24 age group, an Iowan is killed every 2.5 days;
- 29 percent of all motor vehicle crashed involve teens and young adults, even though this age group represents only 18 percent of the total population of Iowa drivers;
- 41 percent of motor vehicle alcohol related deaths involve the 15-24 age group;
- Teenagers do only 20 percent of their driving at night and yet over half of the crash fatalities occur at night.

Prevention measures that target teenagers are of special significance because of the disproportionate level of injury and mortality in this age group. Teenagers are least likely to wear safety belts, yet most likely to be involved in a crash. **Using seat belts can reduce the risk of a traumatic head injury by approximately 41 percent.** Providing passive automatic protection may be the only way to achieve high occupant restraint use rates among this typically non-compliant age group.

**Passive Interventions:** Other automatic protective devices involve the design of vehicles, roads, protective sports gear, etc. These concerns require a larger effort than local initiatives. However, Iowa has active research initiatives in injury prevention underway at both the University of Iowa and Iowa State University.

**Sports and Recreational:** A number of serious injuries and deaths are related to sports and recreational activities. While the majority of sports-related injuries involve the musculoskeletal systems, collision/contact sports injuries may also involve the central nervous system. Direct



evidence links brain damage to sports where repeated blows to the head are common, such as in boxing and football. The effects of such injuries are cumulative and may result in permanent structural changes to the brain.

Systematic documentation of sports injuries in general, and sports-related brain injuries in particular is limited. The tendency has been to report the fatal and severe injuries while ignoring the effects of mild, yet significant, injury to the brain which can result in disability, considerable medical care costs, and lost productivity. Concussions which can cause serious disabilities may never reach the attention of a physician or skilled health care professional.

#### **REVIEW OF 1994 ACCOMPLISHMENTS:**

Collaborated with the Iowa Head Injury Association, University of Iowa Injury Prevention Center, National Highway Transportation Department, Blue Cross /Blue Shield, Principal Financial Group and numerous other agencies to sponsor a Bicycle and Motorcycle Head Injury Prevention Symposium in Iowa City. This symposium was the beginning of a coordinated effort with community groups advocating for Iowa motorcyclists to universally wear motorcycle helmets and universal or partial bicycle helmet legislation. Council members participated in the Iowa Helmet Education Coalition to increase public awareness on the number of deaths and severely injured Iowans in our state. There is sufficient evidence to establish the fact that motorcycle and bicycle helmets do reduce fatalities and injuries that are attributable to motorcycle and bicycle crashes.

Assisted in the development for proposed 1995 legislation for universal motorcycle helmet law and bicycle helmet law.

Participated in the Systems Change and Iowa Head Injury Association Legislative state-wide meetings.

Maintained on-going communication and participation with the Prevention of Disability Policy Council, Iowa SAFE KIDS, Iowa Head Injury Association, and Systems Change Project.

#### **PREVENTION ACTION PLAN 1995**

- **Develop a collaborative and informational network for the coordination of prevention and intervention activities**
  1. Maintain active membership by attending a minimum of four meetings of the Prevention of Disabilities Policy Council.
  2. Maintain active membership by attending a minimum of two meetings annually with the Disability Prevention Advisory Committee, of the Iowa Department of Public Health.
  3. Maintain ongoing support to the Iowa Head Injury Association (IHIA) prevention and intervention activities.



4. Provide support to the Traumatic Injury Prevention Strategies program (TIPS/THINK FIRST) and legislative issues, by providing data and technical assistance as requested.
  5. Maintain ongoing involvement with Iowa SAFE KIDS Coalition to coordinate efforts by attending regular meetings.
- **Coordinate literature and audio visual materials with the Iowa Head Injury Association**
    1. Maintain an ongoing collection of current informational materials on Traumatic Brain Injury.
    2. Publicize the availability of material by writing articles for the "Iowa News" Newsletter from the Iowa Department of Education, Bureau of Special Education, the "Turning Point" Newsletter from the Iowa Systems Change Project, the Iowa Head Injury Association Newsletter, "Prevention Advocate" Newsletter from the Bureau of Injury and Disability within the Iowa Department of Public Health and the "On-Line" Newsletter of the Iowa Rehabilitation Technology Association.
    3. Meet with the Iowa Head Injury Association (IHIA) semi-annually to review materials in order to provide consistency of Traumatic Brain Injury materials.
  - **Develop and support a legislative agenda for 1995 which addresses the following:**
    1. Support effective bicycle legislation, enforcement and educational campaigns.
    2. Support effective motorcycle legislation that conforms to federal recommendations.
    3. Support change for seat belt laws to include back seat occupants and mandate that all age groups be restrained.
    4. Promote safety devices such as air bags and three-point safety restraints for both the front and back seats, and promote an increased fine for noncompliance on wearing a seat belt.
    5. Support enforcement of seat belt and anti-OWI laws. Encourage use of seat belts and increase awareness regarding dangers of drug use and driving.
    6. Meet with representatives of the Governor's Traffic Safety Bureau to determine how dollars being diverted from highway construction efforts (due to lack of a universal helmet law that meets federal requirements) could be better utilized toward the prevention of traumatic brain injuries.
    7. Promote efforts toward sustaining Section 153 of the Intermodal Surface Transportation Act of 1991 (ISTEA). (The federal incentive promoting the benefits of mandatory seat belts and motorcycle helmets).
    8. Work with the legislature, corporately and with individual legislators, in the support of initiatives that may lessen the impact of traumatic brain injury.



- **Develop programs to promote head injury awareness through activities during "National Head Injury Awareness Month"**
  1. Develop two news releases and/or public service announcements during awareness week in October 1995 in collaboration with IHIA.
- **Identify groups and funds for developing and implementing intervention and prevention strategies focused on bicycle safety**
  1. Collaborate on awareness and educational campaigns with Iowa SAFE KIDS, Department of Public Health, Department of Education, Iowa Head Injury Association, and Iowa Methodist Medical Center during 1995.



## SERVICE DELIVERY PLAN

### Overview:

Trauma care has improved dramatically in the U.S. resulting in increased rate of survival among persons with TBI. However, it is not enough to simply save a life after the occurrences of a head injury: an individual's quality of life must be considered as well. A coordinated system of appropriate, cost effective, quality, and timely services must be available to assist a survivor in returning to as normal and productive a life as possible.

In Iowa it is estimated that in the last five years, approximately 27,700 persons experienced a TBI. Some 5,700 of these persons did not survive the injury. Of the survivors however, over 4,000 struggle with a range of disabilities as a result of the head injury (Appendix A).

The goal of TBI rehabilitative, support programs and services is to return people with disabilities as the result of TBI, to a meaningful and productive life in the community of their choice.

### Background:

In Iowa, the **array of services** needed to address this disability group is woefully inadequate. Needed services include: transitional living centers, residential group homes, cognitive therapy, assistive devices and equipment, vocational placement and job coaching, adult day care, long term care, personal assistants, case management, leisure programming, psychosocial counseling, and support for independent living. *As a result, persons with brain injury face inordinate obstacles when seeking accessible, affordable, and appropriate care.*

While the ultimate goal is for the survivor to return to community living, it must be recognized that the level of functioning will vary and that some individuals will need lifelong rehabilitative/habilitative services. This is a significant issue for the families of survivors. The three primary funding mechanisms in Iowa for persons with TBI have been third party insurance (including workers compensation, private health, and applicable automobile related coverage), public assistance (including Medicaid, Medicare, and other federal, state, and county assistance), and self-support (personal and/or familial resources). With few exceptions, these sources do not apply to or, in the case of self-support, are not able to pay for the rehabilitation and community support services which are critical to people recovering from a brain injury. The result is families are often left destitute.

No one suggests that the provision of services to persons with disabilities is inexpensive. What is clear is that an investment in a service infrastructure designed to provide an array of rehabilitative options to persons with addressable functional disabilities resulting from brain injury results in significantly less institutionalization, less incarceration, and provides the opportunity for such persons to contribute to the tax base.

With a growing population of persons with disabilities resulting from brain injury, a consensus is beginning to form among survivors, their families, providers and concerned citizens. This consensus has recognized the gap in the array of services presently available. It is also a group that is progressively developing a louder voice in demanding response to the need for community based services.



To address these concerns, the Council will continue to advocate for access to appropriate health and human services for survivors of traumatic brain injuries in a manner that is both cost-effective and that promotes the highest level of independence in the lives of survivors of traumatic brain injury.

## **REVIEW OF 1994 ACCOMPLISHMENTS**

The significant accomplishment of the Service Task Force was providing the research, support, and information for Senate File 2297. This resulted in legislation directing the Department of Human Services to develop a home and community-based waiver for persons with brain injury, and possibly, more importantly, provided funding for dedicated HCBS/BI waiver staff positions with the Department of Human Services. Collaboration between the Council, the Governor, the Department of Human Services, the Department of Public Health, the University of Iowa Public Policy Research Center, the University of Iowa Department of Preventive Medicine, Service Providers, and survivors of brain injury and their families resulted in this successful legislation. The Council acted to coordinate these various groups providing education, information, and recommendations throughout the legislative process.

In addition, the Council continued to address the lack of information regarding the state's current service capacity and the costs associated with current services. To address this deficit, the Council entered into a collaborative effort with the Iowa Department of Public Health and the University of Iowa, Department of Preventive Medicine. This effort has resulted in the development of a comprehensive survey that, in addition to providing detailed information regarding the scope and cost of services, may serve as a basis for a larger ongoing system of statewide surveillance for head injury.

The Service Task Force coordinated presentations to the greater Council from a number of providers in order to increase awareness of service options and obstacles. These providers included Victorian Acres, Exceptional Persons, Life Skills, Inc., and Goodwill CORE programming.

Several Council members on the Service Delivery Task Force and Prevention Task Force presented a number of public presentations regarding the status of service delivery with specific focus on the development of a Medicaid waiver for home and community-based services for persons with brain injury.

Members of the Council participated across the state in the Systems Change Project legislative meetings and the Iowa Head Injury Association legislative meetings.

Members of the Council collaborated with the Iowa Head Injury Association to inform and educate legislators regarding issues related to head injury services.



## **SERVICE DELIVERY ACTION PLAN 1995**

- **Maintain a collaborative and informational network for data collection, program sharing, and outcome reporting**
  1. Coordinate presentations from a minimum of four different providers to promote Council members awareness.
  2. Respond to requests for educational programming regarding service provision issues.
  3. Continue to provide input to appropriate sources regarding service standard development.
  
- **Collaborate with the Department of Human Services in the development and implementation of the Home and Community-Based Services Waiver for persons with brain injury.**
  1. Continue to assist in the development of a Home and Community-Based Service waiver for TBI.
  2. Collaborate with the Department of Human Services, the Governor, the Iowa Department of Public Health, and the University of Iowa Department of Preventive Medicine to assess statewide capacity and cost of services delivery.
  3. Continue to advocate for the addition of TBI to the Code of Iowa to ensure that the small gains for TBI don't perish with the yearly DHS appropriations language AND to allow Department of Management to track county-by-county expenditures for TBI.
  
- **Coordinate traumatic brain injury service resource materials utilizing data base and the proposed survey to be conducted by the Council.**
  1. Request additional funding, if needed, from the Department of Public Health to extend the Councils' ability to gather and provide information via surveys, educational papers, or TBI consultants.
  2. Provide assistance to IHIA and Iowa Compass to increase the availability of head injury specific information and referral sources for persons with brain injury and their families.
  3. Implement and analyze results from a statewide survey of TBI services by July 1, 1995.



# CENTRAL REGISTRY FOR BRAIN AND SPINAL CORD INJURIES

## **Background:**

In 1989, the Iowa General Assembly passed, and the Governor signed into law, legislation transferring responsibility for administering the Iowa Central Registry for Brain and Spinal Cord Injuries from the Iowa Department of Human Services to the Department of Public Health (IDPH). The Registry had been in existence for one and one-half years at the time of the transfer.

## **Overview:**

Injury prevention specialists and others agree that most injuries are preventable. Head injuries are the leading cause of short and long term disability in Iowa and the United States.

Data on the occurrence and severity of head injuries needs to be collected for the following reasons. First, to effectively target those at an increased risk for sustaining head injuries, we need to collect data such as age, sex, county of residence, and county of occurrence of those injured. Second, to design prevention strategies that reduce the occurrence and severity of head injuries. Third, to determine the costs associated with the occurrence of specific types of head injuries. Fourth, to evaluate the interventions and the occurrence and severity of TBI.

An additional mechanism for tracking persons with brain injuries from acute care to rehabilitation to community living is being conducted through a feasibility study that was granted to the University of Iowa Injury Prevention Center and is being staffed by the Department of Public Health and the Iowa Advisory Council on Head Injury. This study will increase the understanding of the rehabilitation of persons with brain injury in Iowa by assessing existing services and programs.

## **Current Registry Mandate:**

The Iowa Department of Public Health, in cooperation with the Centers for Disease Control-Prevention and endorsed by the Governor's Advisory Council, requested the 1994 legislature to narrow the focus by only collecting data on hospitalized patients, traumatic head injuries, and anoxia (lack of oxygen), thereby excluding nontraumatic events (e.g., vascular lesions, infections). Information about those conditions deleted from the registry's mandate are readily available through hospital discharge data and death certificates. These changes allow the Registry to collect in-depth, valid and reliable data on hospitalized patients, since this group represents the most severely injured with the largest potential for costly future disabilities. Nontraumatic head injuries will still be available through the Bureau of Injury and Disability Prevention by combining data from the above mentioned reporting sources.

Iowa Code 135.22 defines a brain injury only as it relates for data the Registry's is responsible for collecting. It defines a "brain injury" as clinically evident brain damage or spinal cord injury resulting from trauma or anoxia which temporally or permanently impairs a person's physical or cognitive functions.

Data to be collected, includes but is not limited, to patient demographics, circumstances surrounding the injury, measures of the severity of the injury, the use of protective devices,



payment source for medical care. Currently 18 hospitals are collecting data electronically, capturing more than 50 percent of all hospitalized persons with brain injuries. The remaining Iowa hospitals have the option of submitting data electronically or in writing. Hospitals have started to report data using the new definition as reflected in the Iowa Code 135.22 on the updated reporting form, beginning January 1995.

During the past year, Registry data have been used for prevention programs such as bicycle safety, and child-passenger restraint programs. We plan on continuing to expand the possibilities of the Registry for intervention and prevention projects such as utilizing grants in collaboration with other related agencies interested in preventing falls in the elderly.

## **INCIDENCE**

### **Background:**

Based on national estimates, Iowans can expect 5,000-10,000 brain injuries serious enough to require medical treatment. Of the number of Iowans who sustain brain injuries each year, it is estimated that:

- 350-700 will die;
- 1,500-2,000 will be hospitalized for moderate to severe head trauma.
- 4,000-5,000 will be hospitalized for minor head trauma; and

Of those with moderate to severe brain trauma, an estimated 1,000 will become permanently disabled physically, mentally or both.

Lifetime rehabilitation costs for survivors that are severely brain damaged are estimated at \$4 million.

Total medical cost of persons sustaining brain and spinal cord injuries in Iowa are estimated to be between \$350 million to \$400 million per year. Brain injuries account for approximately two-thirds of this cost.

### **Overview:**

Iowa Code requires that injuries to the brain and spinal cord that result "directly or indirectly from trauma, infection, anoxia, or vascular lesions not primarily related to degenerative or aging processes" are to be reported to the Department of Public Health Central Registry. In 1993, a total of 7,044 such injuries were reported (Appendix B).

E-Codes (cause of injuries) are used to categorize injuries. Some of the data collected from our 1993 reports are reflected in the summary statements listed below.



Iowa follows the national trend with males experiencing 60 percent (3,313) of the traumatic brain injuries reported. Females experienced 40 percent (1,715) traumatic brain injuries, a change from last year's pattern of 62 percent males and 38 percent females (Appendices D and E).

"Falls" constitute the majority of traumatic brain injuries reported and include falls from buildings, downstairs, tripping, and slipping. Children under 5 years old and females over the age of 65 represent the ages where the majority of injuries are being sustained from falls. Children under 5 years old account for 529 of the reported falls, and females over age 65 represent 287 of the reported falls. There were 2,214 falls reported during calendar year 1993 (Appendix F).

Motor vehicle injuries are the leading cause of hospitalized traumatic brain injuries and the second leading cause of overall traumatic brain injuries in Iowa. Included are motor vehicles, motorcycles/mopeds, and pedestrians. Of the 1,343 other vehicle crashes, 242 involved injuries to females age 15-24, while 311 involved males age 15-24 (Appendices D and E). Alcohol use is often associated with motor vehicle injuries (Appendix G).

"Intentional" injuries are the third major cause of traumatic brain injury and include assaults, child battering, and suicides. Assaults are the largest sub-category with males involved in over twice as many assaults as females. Of the 435 assaults reported, 300 injuries were to males and 135 were to females (Appendices D and E).

The Registry also compiled data to reflect the numbers of individuals hospitalized due to traumatic brain injuries (Appendices H ).

## **CENTRAL REGISTRY'S ACTION PLAN FOR 1995**

- **Maintain collaboration and coordination with the Central Registry**
  1. The Council shall maintain ongoing communication with the Registry's liaison by reviewing the quarterly reports.
  2. Review the Registry statistics to determine trends in demographics of traumatic brain injuries and inform the Governor and other interested organizations and groups about incidence, costs, and causes of brain injuries as needed and in the annual report.
  3. The Department of Public Health is collaborating with other data base systems within to centralize and streamline data from hospitals, the Bureau of Emergency Services and the Registry.
- **Identify areas of need for facilities and services for survivors of TBI and their families**
  1. Analyze feasibility survey data to determine specific geographic locations within Iowa lacking in services and community-based programs.
  2. Provide appropriate recommendations to the Governor and legislators based on data analysis as needed and in the annual report.
  3. Iowa Department of Public Health is assessing the quality of the Registry's data by using other data sources such as hospital discharge data.



## COUNCIL ACCOMPLISHMENTS

### The Council:

- Collaborated with the Iowa Head Injury Association, University of Iowa Injury Prevention Center, National Highway Transportation Department, Blue Cross /Blue Shield, Principal Financial Group and numerous other agencies to sponsor a Bicycle and Motorcycle Head Injury Prevention Symposium in Iowa City. This symposium was the beginning of a coordinated effort with community groups advocating for Iowa motorcyclists to universally wear motorcycle helmets and universal or partial bicycle helmet legislation. Council members participated in the Iowa Helmet Coalition to increase public awareness on the number of deaths and severely injured Iowans in our state. There is sufficient evidence to establish the fact that motorcycle helmets do reduce fatalities and injuries that are attributable to motorcycle crashes.
- A Home and Community-Based Medicaid Waiver for persons with head injury was legislated in 1994. The waiver allows individuals who are currently in a medical institution for at least 30 days and whose cost will be equal or less than institutional care to return to their community with needed services.
- Received funds from the Iowa Department of Public Health to collaborate with the University of Iowa Injury Prevention Center on a feasibility study to determine scope and cost of services for persons with head injury. It will also increase the understanding of the rehabilitation process and provide a means for a state-wide surveillance.
- Submitted a proposal to the Governor and an identified legislator on the need for the Department of Human Services to develop and submit a Home and Community-Based Service waiver for Iowans with a brain injury.
- Conducted a preliminary survey with the Department of Public Health to determine the average cost per day in institutionalized settings for persons with brain injury.
- Participated with the Restructuring Task Force in their final recommendations to the Governor and the General Assembly on restructuring the delivery of services for MR/MI/DD/BI.
- Collaborated with the Public Policy Research Group, Iowa City, to review the Medicaid files for persons identified as brain injured and receiving Medicaid reimbursements for services.
- Disseminated an educational report authored by Council Member John Bayless, Ph.D., to provide factual information to legislators and the public about the efficacy of helmet usage by Iowa motorcyclists.
- Supported and provided input to the Iowa Central Registry for Brain and Spinal Cord Injury which enhanced their efforts in the need for prevention and to identify the emerging population of persons with traumatic brain injury. The registry also allowed the Council to provide state and local policy makers with accurate data to make informed decisions about legislative initiatives. The Council funded the registry through a state appropriation for two years and supported efforts for the registry to become self-sufficient through a successful federal grant application.



- Continued to build positive alliances within state agencies, advisory committees, community coalitions and other organizations interested in addressing the needs of the disabled community. Furthermore, staff regularly attended the meetings of the Iowa Commission of Persons with Disabilities, Iowa Department of Education - Head Injury Advisory Committee, the Iowa Department of Public Health - Disability Prevention Advisory Committee, Prevention of Disability Policy Council, Iowa SAFE KIDS Coalition, Restructuring Task Force, and Systems Change Project.
- Collaborated with the University of Iowa Hospitals and Clinics and the Division of Disability Determination, a subdivision of the Division of Vocational Rehabilitation within the Iowa Department of Education to develop a system which allows the "flagging" of specific head injury cases, thereby expediting the qualification process for disability determination. The Council continues to monitor this project.
- Successfully completed the 28E agreement between the Iowa Department of Human Services and the University of Iowa Hospitals and Clinics regarding the coordination of a revolving fund. Under this agreement, University of Iowa Hospitals and Clinics established a revolving fund for payment of needed post-acute care until Medicaid eligibility is determined. Repayment would then be made to the revolving fund, and Medicaid would be billed for the care and services.

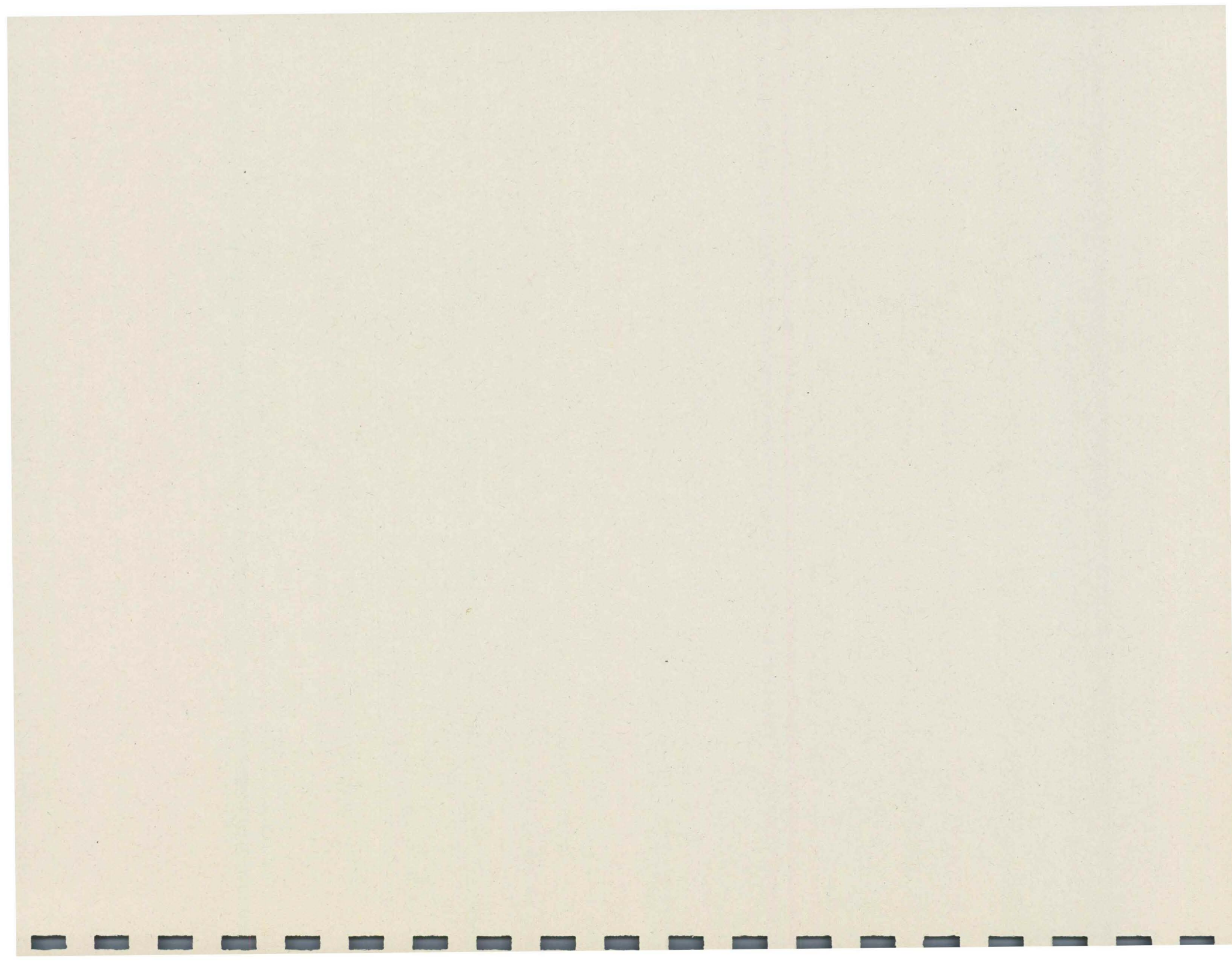
The revolving fund used current funding to save money for the state by:

- Reducing the length of acute hospital stay for persons with head injuries
- Preventing the state from paying higher medical expense rates for persons who, at a later date, are not approved for Medicaid under current policy

This fund has been operational since February 1992. This system could save as much as \$250,000 as documented by an actual study.

- Turned to the excellent services offered through Iowa Compass, a statewide information and referral resource to utilize their data base to develop and continually update a traumatic brain injury service directory for survivors and their families. The Council believes this system is a valuable asset to the state of Iowa and will provide assistance as needed.
- Contributed to the Department of Human Services criteria for facilities providing services to survivors of brain and spinal cord injuries. The Council and other dedicated professionals have formed a committee to make recommendations based on national standards to address the skill level of the professionals, measurable outcomes based on goals, and cost effectiveness for positive and appropriate care of survivors of TBI and their families. Recommendations were finalized and forwarded to DHS and the Iowa Foundation for Medical Care in 1993.
- Initiated communication between the Iowa Department of Human Services, Minnesota's Department of Human Services and area providers to discuss the development of Minnesota's Brain Injury Waiver model and community-based programs. These could be replicated in Iowa to serve survivors of brain injury and their families.







## Voting Members

**Margaret Curry**, Danville, is the Chairperson of the Governor's Advisory Council on Head Injury and founder of the Iowa Head Injury Association, Southeast Area Support Group. She has been an active board member of the Iowa Head Injury Association for several years. She has a daughter who has sustained a traumatic brain injury. She is a member of the Service Provision Task Force.

**Jo Ann C. Kramer**, M.A., Waterloo, is past Chairperson of the Iowa Advisory Council on Head Injuries. She is the founder of the Iowa Head Injury Association and is a Special Education Consultant with Area Education Agency 7. She has a daughter who has sustained a traumatic brain injury. She is a member of the Prevention Task Force.

**Marvin L. Tooman**, Ed.D., Ankeny, is the Chairperson of the Prevention Task Force. He is the Chief Executive Officer of On With Life, Inc. He is a board member of the Iowa Head Injury Association and Chair of the Central Iowa Area Group.

**Geoffry Lauer**, Iowa City, is the Chairperson of the Service Provision Task Force. He is program director of Life Skills, Inc., a home and community-based service delivery program for individuals with a disability.

**Joni Henderson**, Independence, is the Rehabilitation Program Coordinator at Mercy Medical Center. She has extensive experience as a rehabilitation nurse. She is a member of the Service Provision Task Force.

**Deborah J. Hughes**, Cedar Rapids, is an attorney in private practice with Irvine & Robbins in Cedar Rapids. Her practice is focused on the representation of injured persons, including those with head injuries. She is past president of the Professional Women's Network and serves on the Board of Governors of the Iowa Trial Lawyers Association. She is a member of the Prevention Task Force.

**Josephine Gruhn**, Spirit Lake, is a member of the Prevention Task Force. She is a former member of the Iowa House of Representatives.

**James C. Hardy**, Ph.D., Iowa City, is Professor and Director of Professional Services in the Division of Developmental Disabilities at the University of Iowa. He is on the Service Provision Task Force.

**Delbert L. Jensen**, St. Ansgar, is the former Superintendent of Schools in St. Ansgar and is a board member of the Iowa Head Injury Association, the North Central Iowa Group. He sustained a traumatic brain injury in 1986. He serves on the Prevention Task Force.

**Karen A. Johnson**, Davenport, is president of the Iowa Head Injury Association and a long-standing member. She is active in her local Head Injury Support Group. She has two family members who have sustained traumatic brain injuries. She serves on the Service Provision Task Force.

**John May**, M.D., Des Moines, is the Medical Director of Blue Cross/Blue Shield of Iowa. He is a member of the Service Provision Task Force.



**Jeffrey S. Thomas**, Spencer, is a school psychologist for Lakeland Area Agency and team leader for Area Education Agency 3 Head Injury Resource team. He is a member of the Prevention Task Force.

**Laurie Dyer**, Des Moines, is an advocate for children with a head injury. She is a member of Advocate for Special Kids. She has a son who sustained a head injury in 1983 and diagnosed in 1990. She is on the Board of Directors of the Iowa Head Injury Association Central Iowa Support Group, a member of the Iowa Head Injury Association, the National Head Injury Foundation and the System Change Project. Laurie serves on the Service Provision Task Force.

**Robert Schultz**, Burlington, is an inventory specialist with GE for the last 32 years. He is a member of the Southeast Iowa Head Injury Support Group. His wife had a tumor removed in 1984 which left her with some mild deficiencies in day-to-day living skills. Bob serves on the Prevention Task Force.

**Esthyr Ropa**, CRC, Sioux City, is a vocational rehabilitation counselor. She sustained a traumatic head injury in 1985. She is a member of the Service Provision Task Force.

**Kris Tharp**, West Des Moines. Her son was injured in a bicycle/car collision and sustained a head injury that resulted in his death. She has an interest in preventing future fatalities and in investing in quality services for other families whose loved ones survive. She is a member of the Service Provision Task Force.

#### **Ex - Officio Members**

**Christopher Atchison**, Des Moines, is the Director of the Iowa Department of Public Health.

**Almo Hawkins**, Des Moines, is the Director of the Iowa Department of Human Rights.

**Terri Vaughan**, Des Moines, is Commissioner of the Insurance Division of the Iowa Department of Commerce.

**Chuck Palmer**, Des Moines, is the Director of the Iowa Department of Human Services.

**Craig Slayton**, Des Moines, is the Director of the Iowa Department for the Blind.

**Al Ramiriz**, Des Moines, is the Director of the Department of Education.

**Margaret Knudson**, Des Moines, is Administrator of the Vocational Rehabilitation Division, with the Iowa Department of Education.



## **Ex - Officio Representatives**

**Janet Shoeman**, Des Moines, is a Developmental Disabilities Specialist with the Iowa Department of Human Services. She is on the Service Provision Task Force.

**Ruth Burrows**, Des Moines, is on the Service Provision Task Force. She is Bureau Chief of Rehabilitation Resources, Vocational Rehabilitation Division, with the Iowa Department of Education. She is a board member of the Iowa Head Injury Association.

**Roger Chapman**, Des Moines, is Bureau Chief for the Disability and Injury Prevention Program, Division of Substance Abuse and Health Promotion, with the Iowa Department of Public Health.

**Bonnie Linquist**, Des Moines, is a Vocational Rehabilitation Supervisor and is the Facility Specialist for the Iowa Department for the Blind.

**Dr. Jeanne Hagen**, Des Moines, is Bureau Chief for Special Education with the Iowa Department of Education.

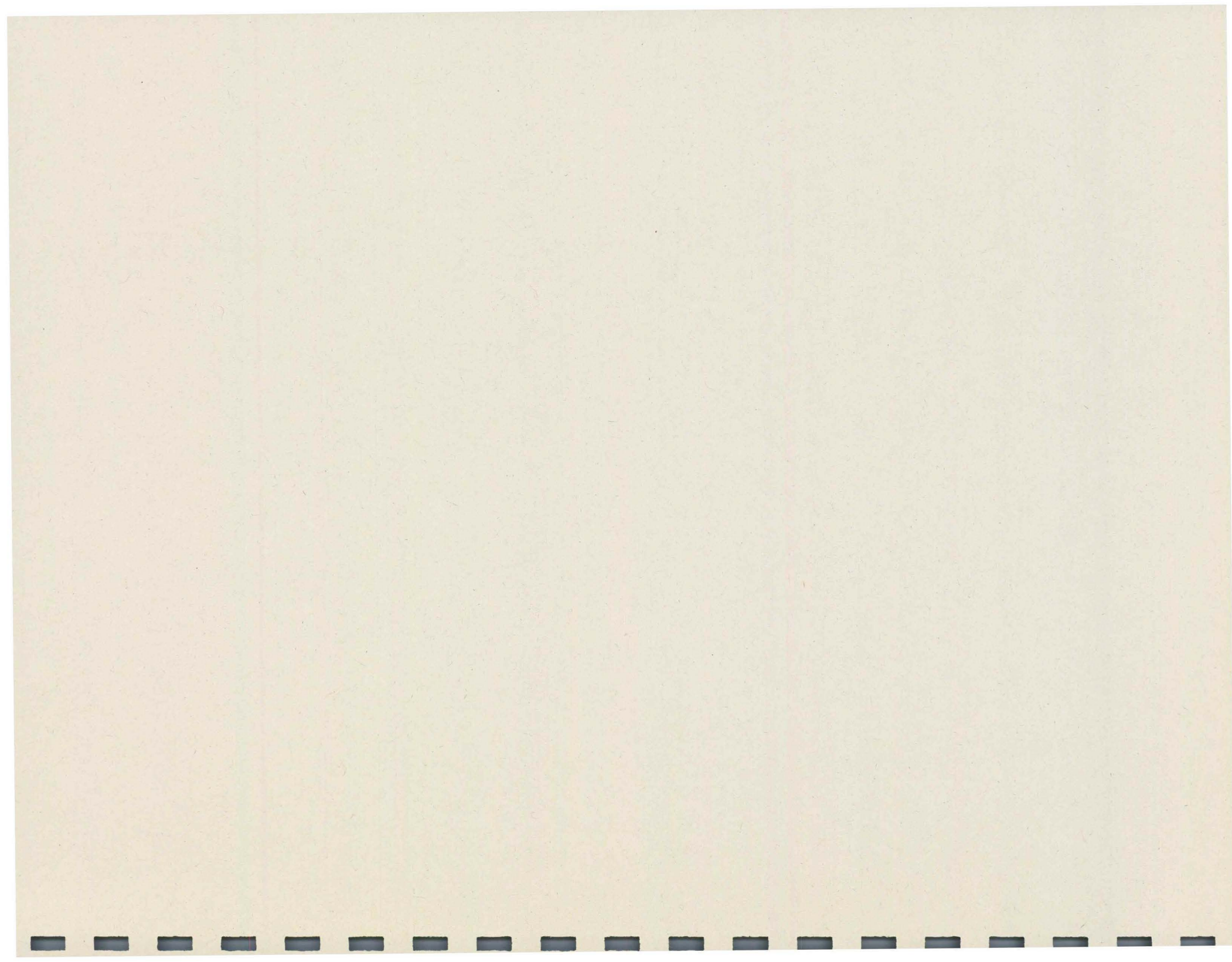
**Dan Winegarden**, Des Moines, is the First Deputy Commissioner for the Division of Insurance with the Iowa Department of Commerce.

**Scott Falb**, Des Moines, is a Driver Services Representative for the Iowa Department of Transportation.

## **Staff**

**Sheila Hourigan**, Des Moines, is the Disability Consultant within the Bureau of Disability and Injury Prevention, Department of Public Health.



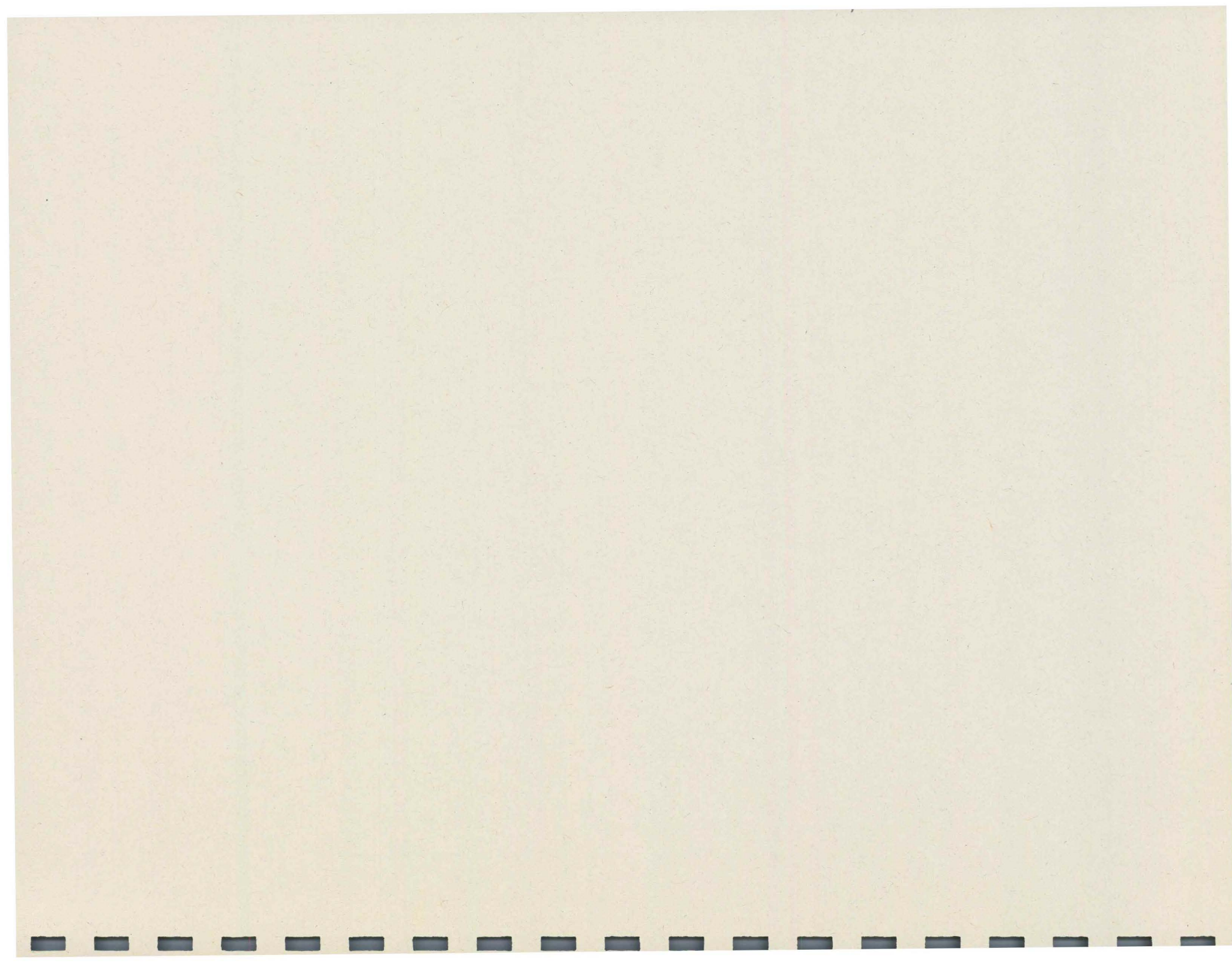




## APPENDICES A - H

- A: Estimates based on U.S. Bureau of Census (1991) and Sorenson, S.B. & Kraus, J.F.
- B: All injuries-Emergency Room Hospitalized-1993
- C: Traumatic Brain Injuries by Counties-1993
- D: Traumatic Brain Injuries treated in Emergency Room and Hospitalized by Cause of Injury and Age for Males-1993
- E: Traumatic Brain Injuries treated in Emergency Room and Hospitalized by Cause of Injury and Age for Females-1993
- F: Traumatic Brain Injury by Cause-1993-Emergency Room and Hospitalized
- G: Traumatic Brain Injuries treated in Emergency Room and Hospitalized-1993 Alcohol-Related by Age and Cause
- H: Hospitalized Traumatic Brain Injuries by Cause of Injury and Age-1993





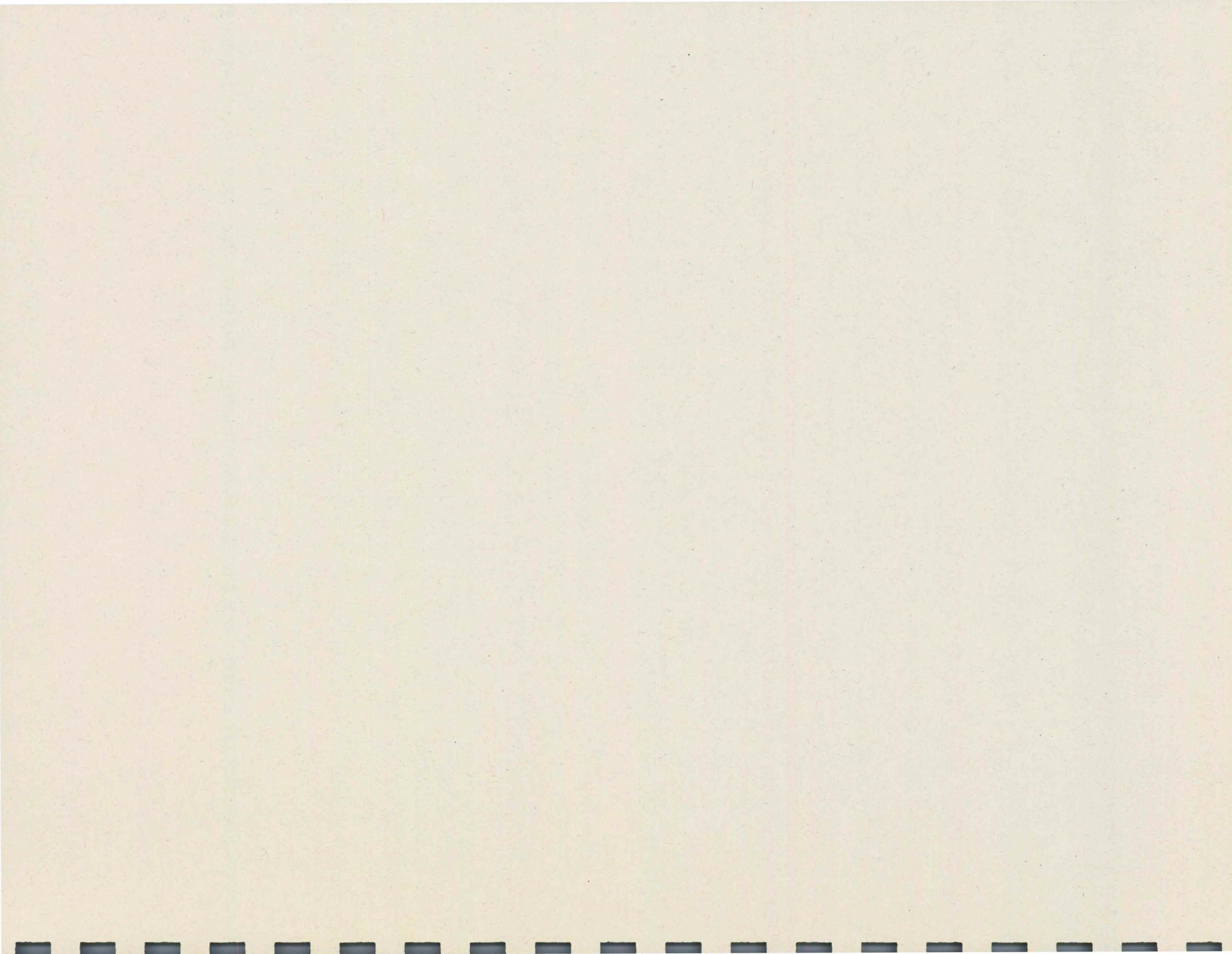


## GEOFFREY LAUER - 9TH ANNUAL TBI CONFERENCE - HCBW/BI - 10/19/94

	No. of persons			
IOWA POPULATION (1990 Census)		2,776,755		
ANNUAL INCIDENCE OF TRAUMATIC BRAIN INJURY (TBI)				
200/100,000		5,554		
IOWA CENTRAL REGISTRY FOR BRAIN AND SPINAL CORD INJURIES				
(1991 - for TBI)		5,353		
-----				
ANNUAL MORTALITY FROM TBI DEATHS OCCURRING PRIOR				
TO HOSPITALIZATION	30/100,000	833		
NUMBER OF PERSONS HOSPITALIZED				
	170/100,000	4,719		
SEVERITY OF INJURY FOR HOSPITALIZED PERSONS WITH TBI				
<u>Injury Severity</u>				
Mild	80% x 4719	3,775		
Moderate	10% x 4719	472		
Severe	10% x 4719	472		
DISCHARGE STATUS OF HOSPITALIZED PERSONS WITH TBI				
<u>Injury Severity</u>	<u>% Alive</u>	<u>No. Alive</u>	<u>% Dead</u>	<u>No. Dead</u>
Mild	100	3775	0	0
Moderate	93	439	7	33
Severe	42	198	58	274
		4412		307
ANNUAL DEATH RATE AMONG HOSPITALIZED PERSONS WITH TBI				
(deaths occurring during hospitalization).				
6502/100,000 x 4719				
307				
ANNUAL INCIDENCE OF DISABILITY DUE TO HEAD INJURY IN THE GENERAL				
POPULATION.				
31/100,000 x 2,776,775				
861				
NUMBER OF PERSONS DISCHARGED WITH LIMITATION OR DISABILITY				
<u>Injury Severity</u>	<u>% with Disability</u>	<u>No. with Disability</u>		
Mild	10% (x 3775)	378		
Moderate	67% (x 439)	294		
Severe	100% (x 198)	198		
		870	870	
TOTAL NUMBER OF TBI DEATHS PER YEAR				
(includes death due to TBI prior to hospitalization)				
833 + 307				
1,140				
TOTAL ANNUAL DEATH RATE				
(includes death due to TBI prior to and during hospitalization)				
41/100,000 x 2,776,775				
1,138				

Estimates based on U.S. Bureau of Census (1991) and Sorenson, S.B. & Kraus, J.F. (1991). Occurrence, severity, and outcome of brain injury, *Journal of Head Trauma Rehabilitation*. 6(2), 1-10.



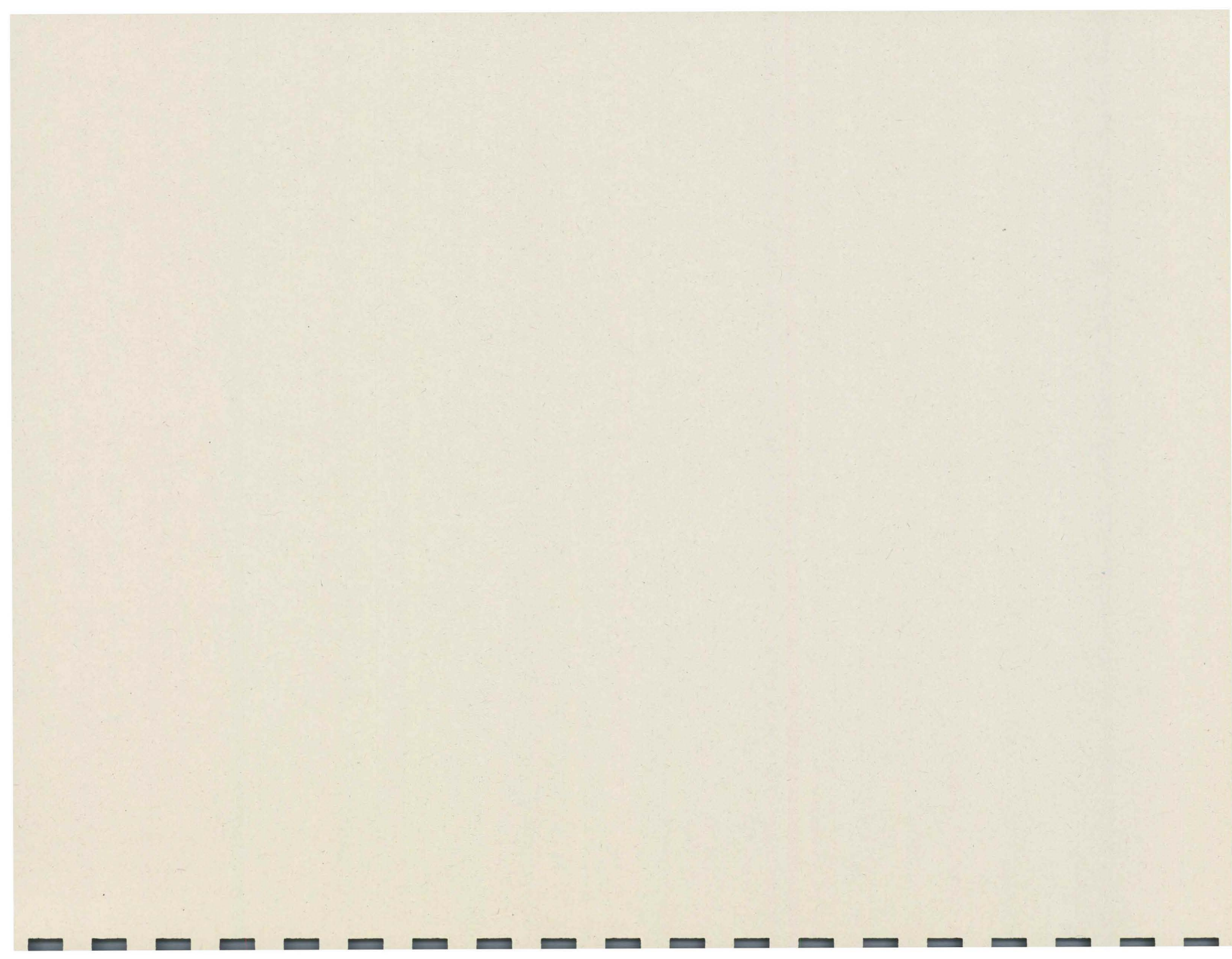




**APPENDIX B****IOWA CENTRAL REGISTRY FOR BRAIN & SPINAL CORD INJURIES  
ALL INJURIES-EMERGENCY ROOMS, HOSPITALS, PHYSICIANS &  
REHABILITATION CENTERS - 1993**

<b>PRIMARY DIAGNOSIS</b>	<b>&lt;1</b>	<b>1-4</b>	<b>5-14</b>	<b>15-24</b>	<b>25-44</b>	<b>45-64</b>	<b>65+</b>	<b>TOTAL</b>
<b>Traumatic Brain</b>	82	680	1041	1376	1250	493	608	5531
<b>Spinal Cord</b>	7	17	54	123	276	180	192	849
<b>Nose, Jaw, Blood Vessels</b>	0	5	61	183	189	40	35	513
<b>Anoxia</b>	0	1	0	3	6	3	3	16
<b>Infection</b>	7	7	18	5	34	24	19	114
<b>Drowning/ Suffocation</b>	0	5	2	3	8	1	2	21
<b>TOTAL</b>	96	715	1176	1693	1764	741	859	
							<b>GRAND TOTAL</b>	7044

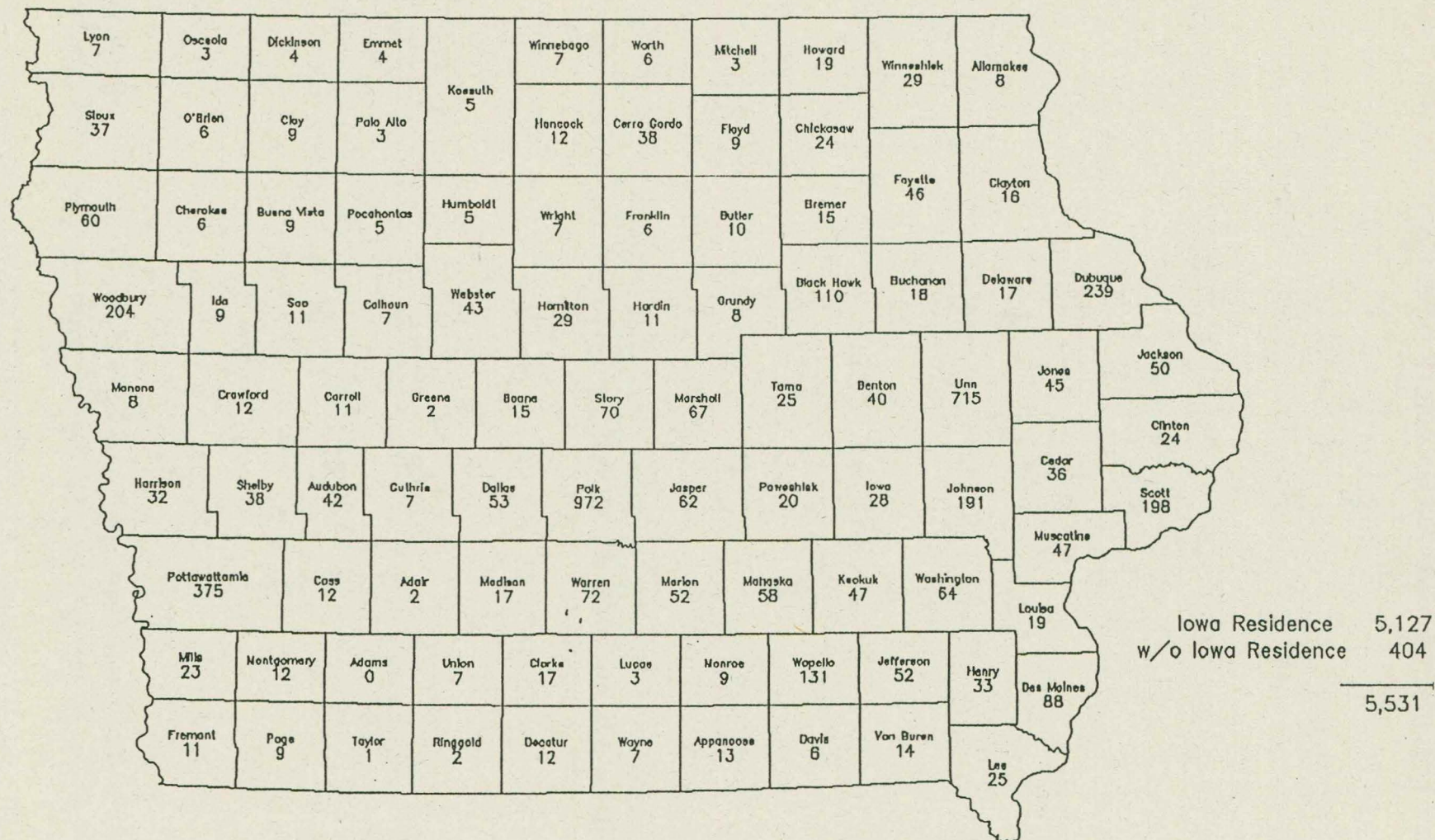




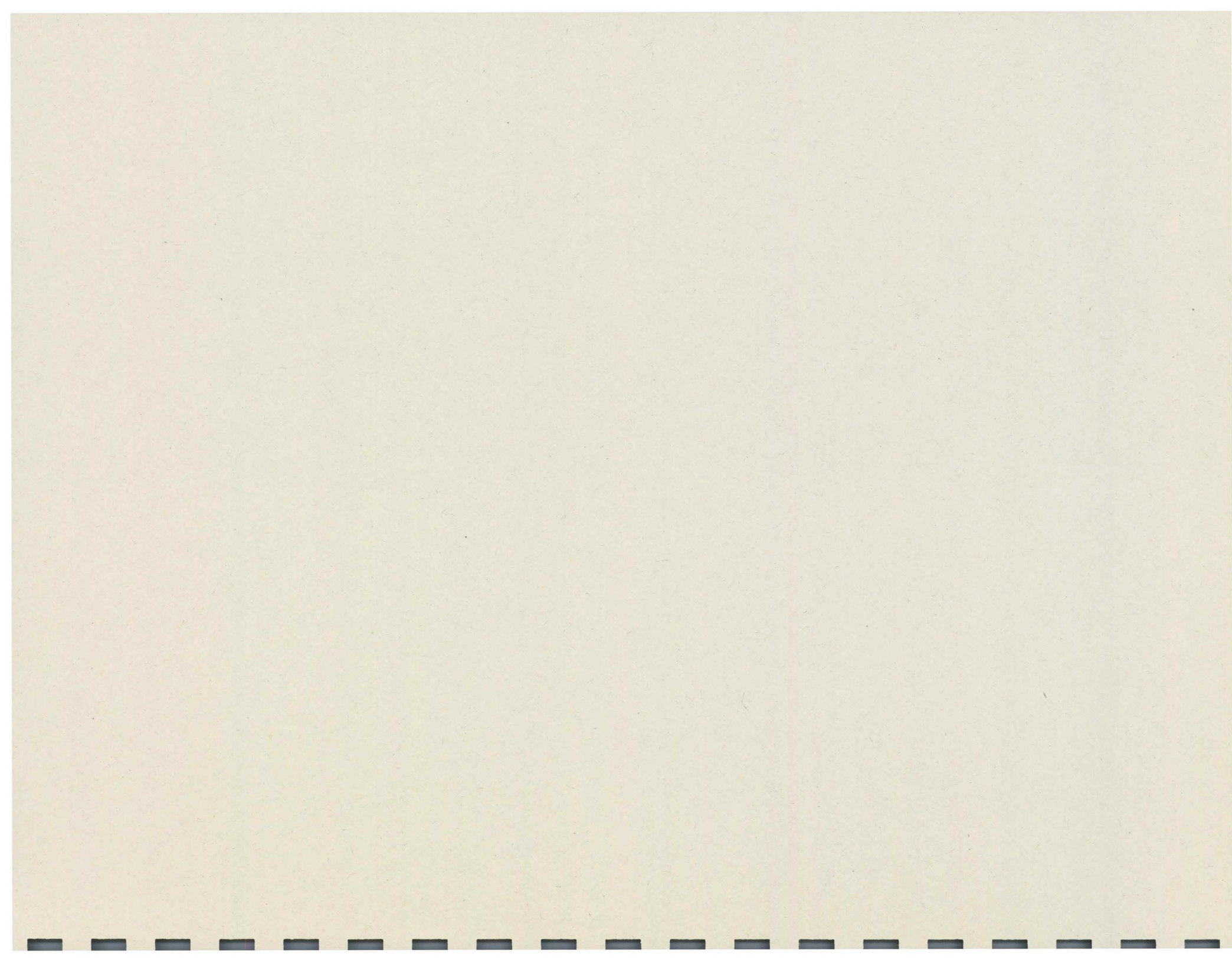


# Iowa Central Registry for Brain and Spinal Cord Injuries, Traumatic Brain Injuries – 1993

Treated by Physicians, ER, Hospitalized









## APPENDIX D

### IOWA CENTRAL REGISTRY FOR BRAIN & SPINAL CORD INJURIES TRAUMATIC BRAIN INJURIES BY CAUSE FOR MALES - 1993

CAUSE OF INJURY	<1	1-4	5-14	15-24	25-44	45-64	65+	TOTAL
*Motor Vehicle	1	15	62	311	231	86	38	744
ATV	0	0	7	9	10	0	1	27
Snowmobile	0	0	0	5	6	0	0	11
Motorcycle	0	0	3	27	37	6	2	75
Pedestrian MV	0	3	28	13	5	2	3	54
All Bicycles	0	5	88	30	20	4	3	150
Falls	34	297	271	116	166	110	192	1186
Assault	3	0	20	133	133	9	2	300
Sports	0	5	80	166	32	2	0	285
Struck By Machine, Environmental, etc.	3	54	87	62	103	34	9	352
Undetermined Intent	0	0	2	6	11	4	0	23
Miscellaneous	0	4	37	20	28	12	5	106
TOTAL	41	383	685	898	782	269	255	3313

\*Excludes ATV's, Snowmobiles, Motorcycles, Pedestrian and Bicycles

## APPENDIX E

### IOWA CENTRAL REGISTRY FOR BRAIN & SPINAL CORD INJURIES TRAUMATIC BRAIN INJURIES BY CAUSE FOR FEMALES - 1993

CAUSE OF INJURY	<1	1-4	5-14	15-24	25-44	45-64	65+	TOTAL
*Motor Vehicle	1	20	46	242	177	70	43	599
ATV	0	0	2	0	0	0	0	2
Snowmobile	0	0	1	0	0	0	0	1
Motorcycle	0	0	0	7	6	0	0	13
Pedestrian MV	0	2	12	3	8	7	3	35
All Bicycles	0	2	54	10	9	4	0	79
Falls	30	231	150	100	134	96	287	1028
Assault	4	4	5	55	59	8	0	135
Sports	0	4	22	25	10	5	0	66
Struck By Machine, Environmental, etc.	6	33	40	20	44	21	15	179
Undetermined Intent	0	0	0	1	2	0	0	3
Miscellaneous	0	1	24	15	20	13	5	78
TOTAL	41	297	356	478	469	224	353	2218

\*Excludes ATV's, Snowmobiles, Motorcycles, Pedestrians and Bicycles

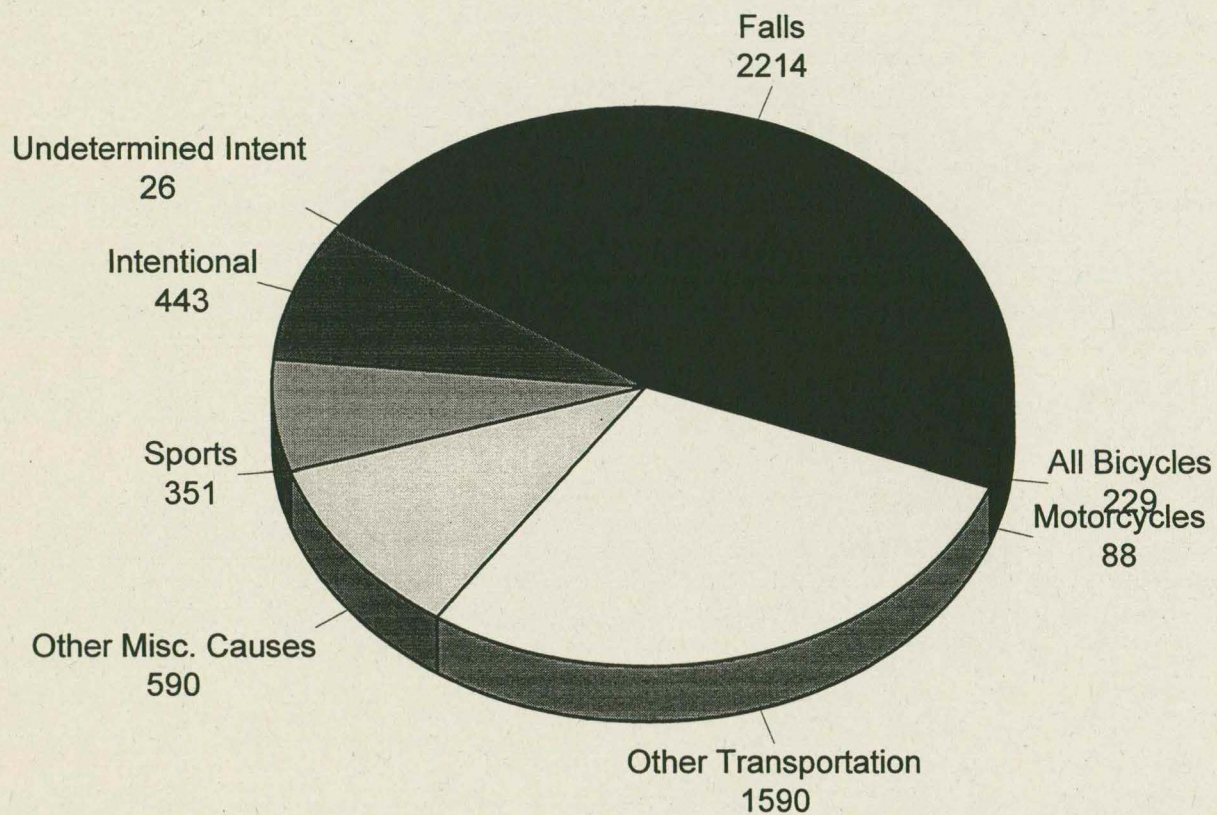






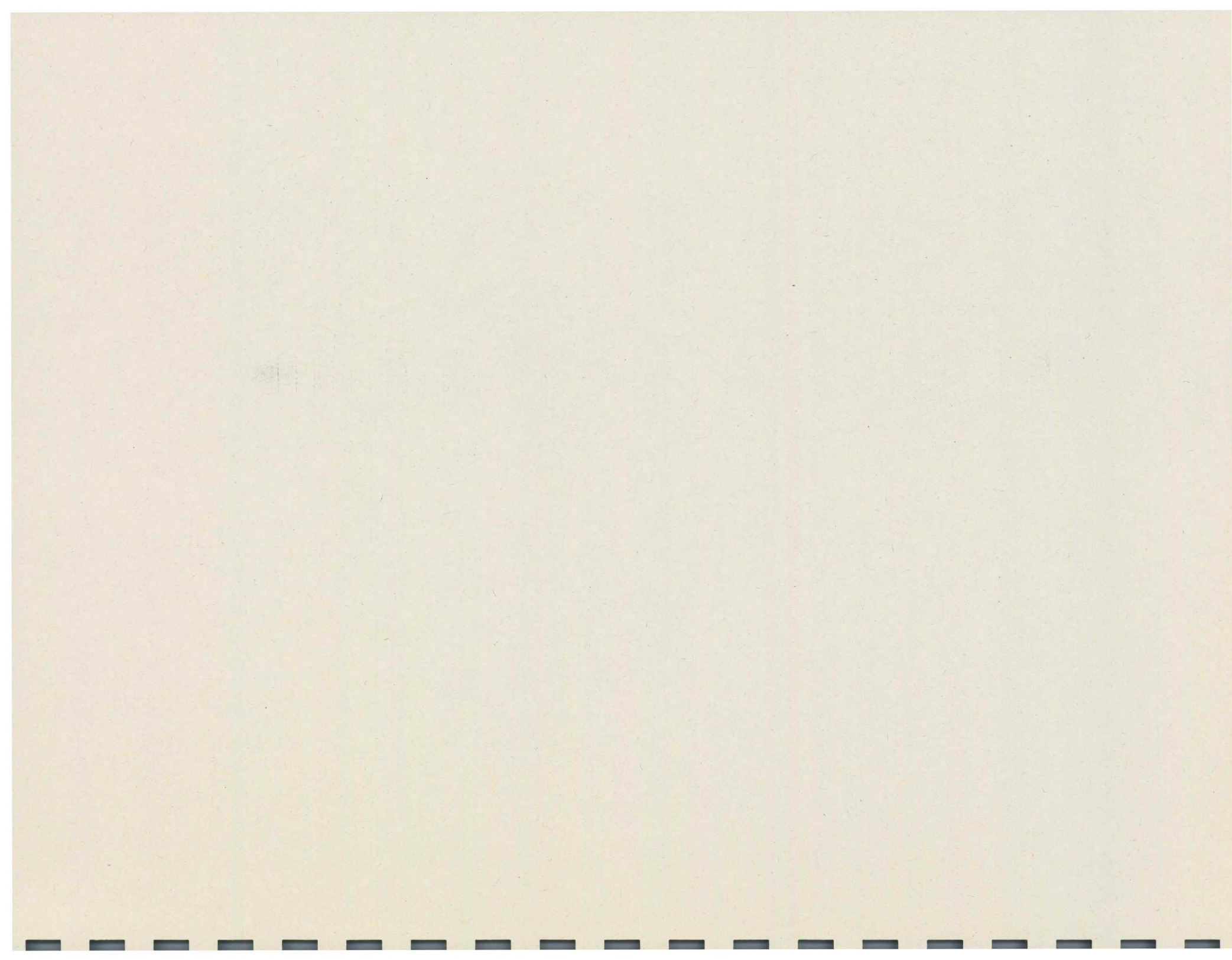
# Iowa Central Registry for Brain and Spinal Cord Injuries

## Traumatic Brain Injuries by Cause - All Reports 1993



n=5531







## APPENDIX G

### IOWA CENTRAL REGISTRY FOR BRAIN & SPINAL CORD INJURIES HOSPITALIZED TRAUMATIC BRAIN INJURIES BY CAUSE WITH ALCOHOL INVOLVEMENT- 1993

CAUSE OF INJURY	<1	1-4	5-14	15-24	25-44	45-64	65+	TOTAL
*Motor Vehicle	0	0	2	54	55	11	0	122
ATV	0	0	0	1	3	0	0	4
Snowmobile	0	0	0	1	3	0	0	4
Motorcycle	0	0	0	5	17	2	0	24
Pedestrian MV	0	0	0	1	1	0	0	2
All Bicycles	0	0	0	5	0	0	0	5
Falls	0	1	1	3	26	12	13	56
Assault	0	0	0	39	57	4	0	100
Sports	0	0	0	0	0	0	0	0
Struck By Machine, Environmental, etc.	0	0	1	3	2	0	1	7
Undetermined Intent	0	0	0	0	3	1	0	4
Miscellaneous	0	0	1	2	1	1	0	5
TOTAL	0	1	5	109	173	31	14	333

\*Excludes ATV's, Snowmobiles, Motorcycles, Pedestrians and Bicycles

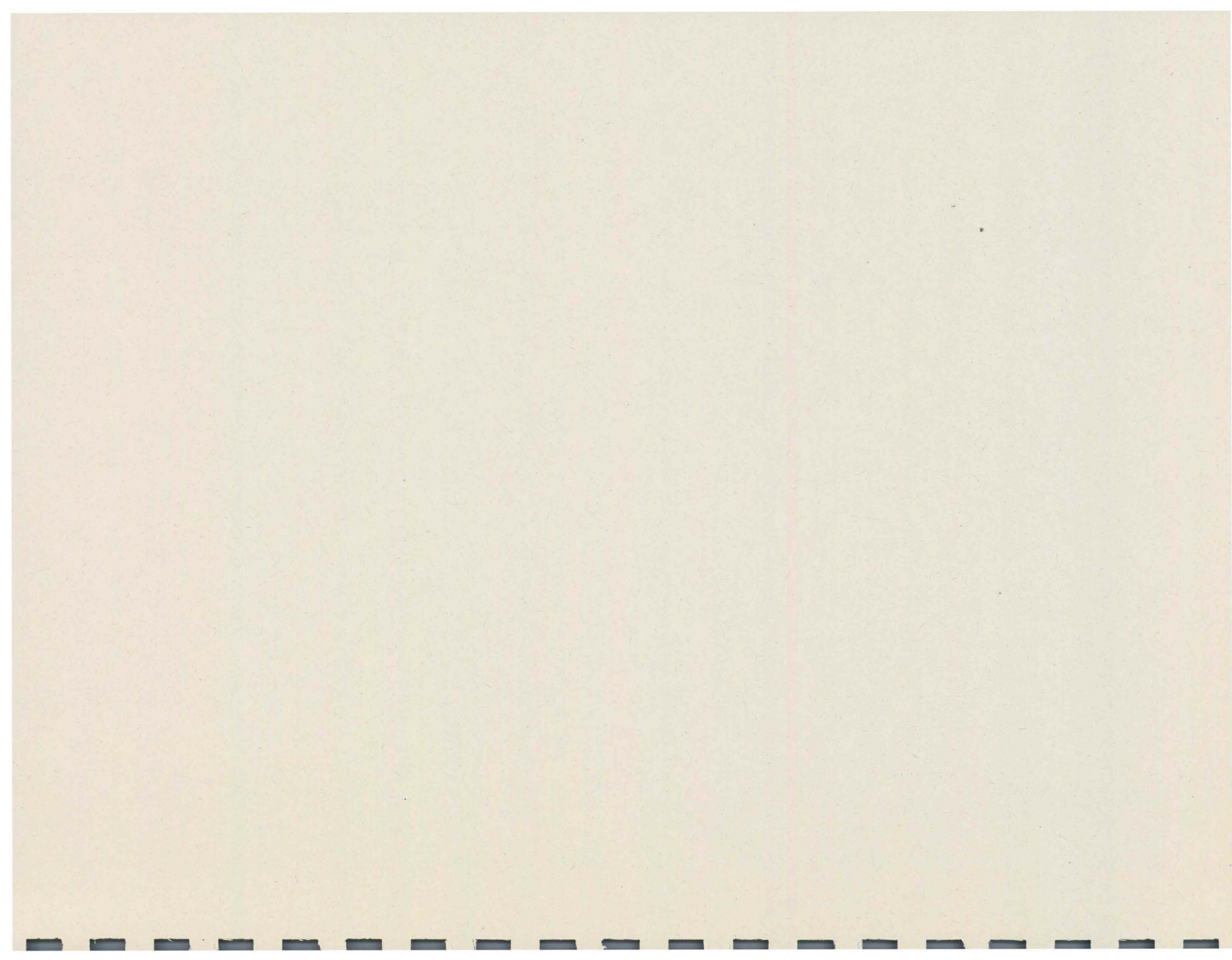
## APPENDIX H

### IOWA CENTRAL REGISTRY FOR BRAIN & SPINAL CORD INJURIES HOSPITALIZED TRAUMATIC BRAIN INJURIES BY CAUSE - 1993

CAUSE OF INJURY	<1	1-4	5-14	15-24	25-44	45-64	65+	TOTAL
*Motor Vehicle	1	14	33	210	163	76	48	545
ATV	0	0	2	5	4	0	1	12
Snowmobile	0	0	1	2	5	0	0	8
*Motorcycle	0	0	3	24	28	5	1	61
Pedestrian MV	0	2	19	9	9	8	6	53
All Bicycles	0	2	45	14	11	3	1	76
Falls	13	59	62	29	73	75	231	542
Assault	6	3	6	30	48	5	1	99
Sports	0	1	14	25	3	1	0	44
Struck By Machine, Environmental, etc.	3	9	15	13	29	14	10	93
Undetermined Intent	0	0	1	4	12	3	0	20
Miscellaneous	0	2	23	14	27	15	9	90
TOTAL	23	92	224	379	412	205	308	1643

\*Excludes ATV's, Snowmobiles, Motorcycles, Pedestrian and Bicycles







## **ADDENDUM 1: RESOURCES**

**Iowa's Educational Network for Brain Injury**

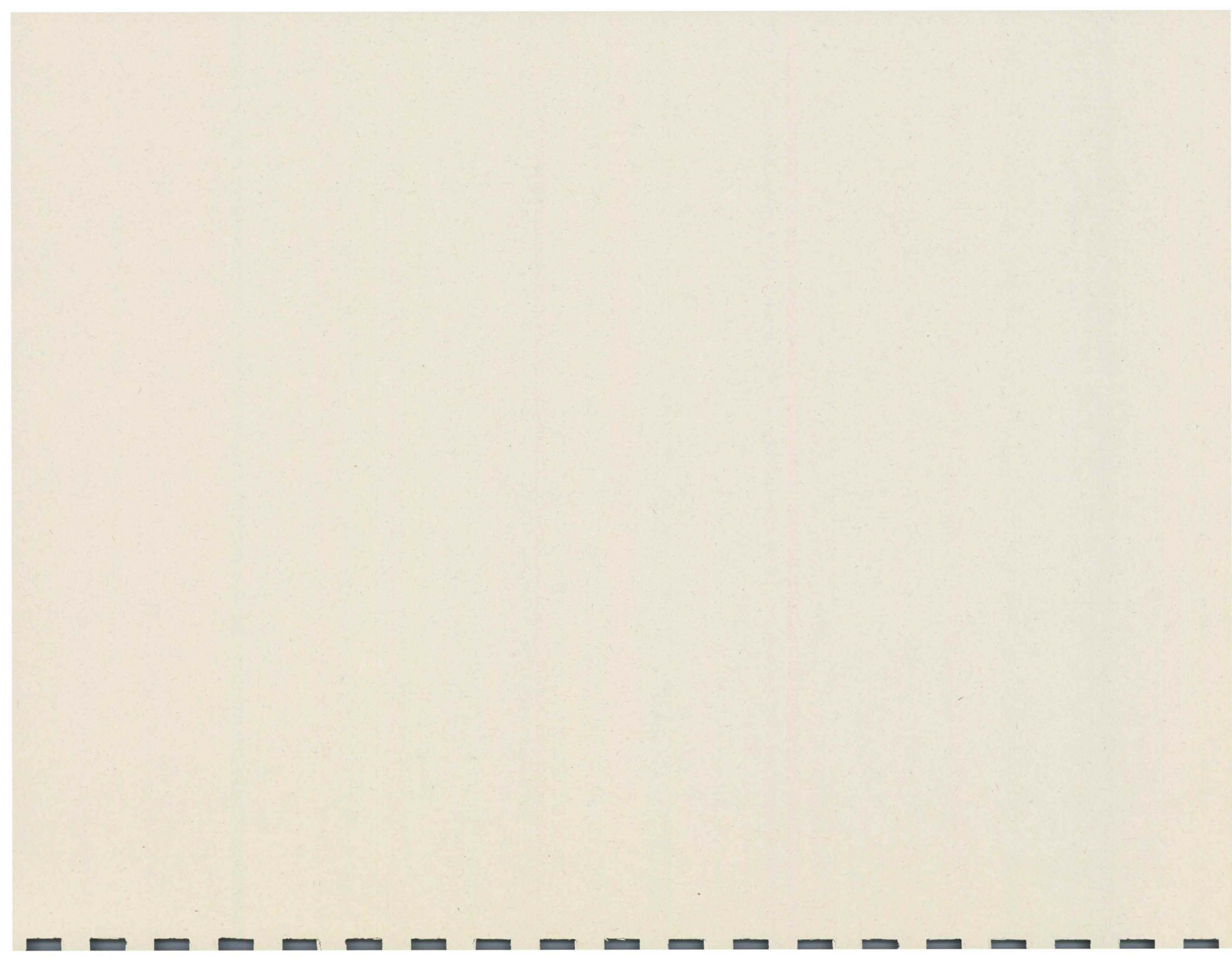
**Pediatric Brain Injury Services**

**Support Groups**

**Iowa Head Injury Association**

**Iowa Compass**







## **ADDENDUM 1: RESOURCES**

### **IOWA'S EDUCATIONAL NETWORK FOR BRAIN INJURY**

In the spring of 1988, the Iowa Bureau of Special Education formed a task force to identify issues and make recommendations regarding educational programs and services for students who had experienced head injuries. One recommendation was to create Head Injury Resource Teams in each Area Education Agency (AEA) for the purpose of working with local school personnel, and to provide assistance and support to the families of these children.

The Head Injury Resource Teams are multi-disciplinary and may include representatives from nursing, psychology, education, social work, speech/language pathology, occupational therapy, and physical therapy. Each team has a specific contact person to facilitate communication with other agencies.

The teams have participated in numerous workshops and conferences in order to increase their skills and expertise as consultants. In turn, team members have provided in-service presentations to schools, emergency medical personnel, parent groups and other agencies in order to increase knowledge and awareness of head injury.

The Iowa Model for School ReEntry is a document that was created by the Head Injury Teams. It is designed to assist students in making a smoother transition back to the classroom following a head injury. The Re-Entry model helps to ensure that the student's medical, educational, social and emotional needs are identified and met, and also emphasizes the importance of communication between medical and school agencies and the family.

Prevention of head injury is a goal shared by all the resource teams. The most common causes listed for head injuries in this age group were from motor vehicle crashes, falls, assaults, and bicycle crashes. The Head Injury Resource Teams work with other community agencies and organizations in designing prevention activities which include farm safety for children, bicycle safety, use of seat belts/car seats, and playground safety.

For further information about the teams and their functions, contact Sue Pearson, State Consultant for Head Injury, at the University of Iowa (319) 356-1172.



## ADDENDUM: 1

### PEDIATRIC BRAIN INJURY SERVICE

A comprehensive interdisciplinary evaluative and therapeutic service for children following a brain injury is being offered by the Division of Developmental Disabilities at the University of Iowa Hospital School.

Populations served by the Pediatric Brain Injury Team include:

- the individual who is leaving a critical care setting and is in need of short-term intensive therapy services;
- the individual who has completed post-acute rehabilitation and is attempting reintegration into school, work, and community.

Emphasis is placed on:

- evaluation and management of cognitive, emotional and behavioral deficits.
- neuropsychological assessment.
- evaluation and management of motor deficits.
- assistance with performing activities of daily living.
- fabrication of postural support systems.
- evaluation and management of feeding difficulties.
- provision of educational evaluations with recommendations for educational programming.

The Pediatric Brain Injury Team includes a pediatrician, specialized nursing staff, neuropsychologist, education consultant, occupational therapist, physical therapist, speech-language pathologist, social worker, nutritionist, and therapeutic recreation specialist. The family and patient are also important team members. Depending on the specific needs of the individual, professionals in the fields of child psychiatry, dentistry, rehabilitation engineering and audiology are also available for consultation.

Both inpatient and outpatient evaluations focus on the following goals for the individual who has a brain injury:

- identification of specific problem areas.
- provision of ongoing follow-up services to meet the changing needs of the individual and his or her family.
- identification of additional services for the individual through either local services or the University of Iowa Hospitals and Clinics.
- assistance to local school personnel to facilitate reintegration of the individual into a specific school program.

For further information call:

Inpatient: (319) 356-7404 (Voice)  
(319) 353-6805 (TTY)

Outpatient: (319) 356-0721 (Voice)  
(319) 353-6805 (TTY)



## **ADDENDUM: 1**

### **SUPPORT GROUPS**

Parents of young children, families of teenagers and young adults, spouses, children and siblings of those who are injured, survivors in wheelchairs, survivors with other physical problems, those with slurred speech, memory loss, diminished attention spans or ability to organize or follow directions, those who can't return to former jobs, whose marriages and personal relationships are shattered, whose personalities are dramatically changed. How can we offer meaningful support to all of them! It is a reminder of the tremendous challenge we face in responding to the diverse needs of families and survivors.

Head injury support groups are one of the key elements of a successful network of support. Support groups should accommodate the unique needs of the individuals requiring support. This can occur in a group setting for either specialized groups such as school-aged children, spouses, or may be all encompassing. It can be defined as linking one person to another or one family with another. The success of the support network is measured only by the participants.

Support groups help survivors and family members realize they are not alone, provide updated information, community resources, and coping strategies for the lifelong changes associated with a traumatic brain injury.

Support groups may prevent secondary disabilities related to brain injuries (divorce, chemical dependency, mental health problems, isolation, etc.) by providing the emotional and informational support lacking in our current systems. Since Iowa is primarily a rural state, the support group may be the only source of solace for survivors and/or their families.

There are 15 area support groups scattered throughout Iowa. For more information on joining or beginning a support group in your area, call the Iowa Head Injury Association at (319) 291-3552 or Sheila Hourigan, Disability Consultant at (515) 281-6283.



## **ADDENDUM: 1**

### **IOWA HEAD INJURY ASSOCIATION**

Iowa Head Injury Association (IHIA) was organized to speak out on behalf of all survivors of head injury and their families. Founded in 1980, the IHIA is the second charter chapter of the National Head Injury Foundation. People with head injury, their families, friends, and professionals organized to improve the quality of life for survivors, to prevent the incidence of head injury, and to advocate for services vital to persons with head injury and their families.

Dedicated members work together to increase the public's awareness of head injury and its consequences, develop support systems, encourage appropriate rehabilitation for survivors, and disseminate information regarding head injury.

The organization's advocacy efforts have resulted in legislation being enacted to establish an Advisory Council on Head Injury, a Brain Injury Registry, and recognition of head injury as a separate disability through the Category Bill.

IHIA sponsors educational programs for families and professionals. "BRAINSTORMING," the IHIA Newsletter, reports new developments in the field and apprises members of available services and upcoming events. On the local level, there are 15 area support groups which are invaluable for exchanging experiences, advice, and assistance to one another.

IHIA is actively involved in prevention of head injury. In January of 1987, the Traumatic Injury Prevention Strategies (TIPS) program began in Iowa. Since the inception of TIPS, over 65,000 Iowa students have heard this important message. TIPS is a school-based assembly program geared toward students and focuses on prevention of head injuries through the use of seat belts, helmets, driving safely, driving chemically free, and use of common sense. The program is a fast paced, upbeat, attention-holding presentation which uses a factual peer-to-peer approach.

IHIA believes that everyone facing life after head injury deserves the opportunity to achieve maximum functioning. Therefore, the association advocates statewide public and private funding to pay for services.



## ADDENDUM: 1

### IOWA COMPASS

Iowa Compass is an informational and resource referral source for Iowans with disabilities and their families. Iowa Compass provides services to all Iowans with disabilities, family members, service providers, and other community members.

Iowa Compass provides Iowans with no-cost, specific, confidential, and up-to-date information regarding services and supportive programs through an accessible toll-free number. Iowans can also access information through the mail or on audio cassette. Compass collaborates and recognizes the existence of other information and referral systems throughout the state and nation.

The services Iowa Compass provides include:

Advocacy/Legal Aid  
Assistive Technology  
Community Services to Meet Basic Needs  
Health Care and Specialized Therapies  
Individual and Family Support  
Public Awareness Activities  
Mental Health Services  
Transportation  
Service Provider addresses,  
phone numbers and contact persons  
Services for persons with specific disabilities

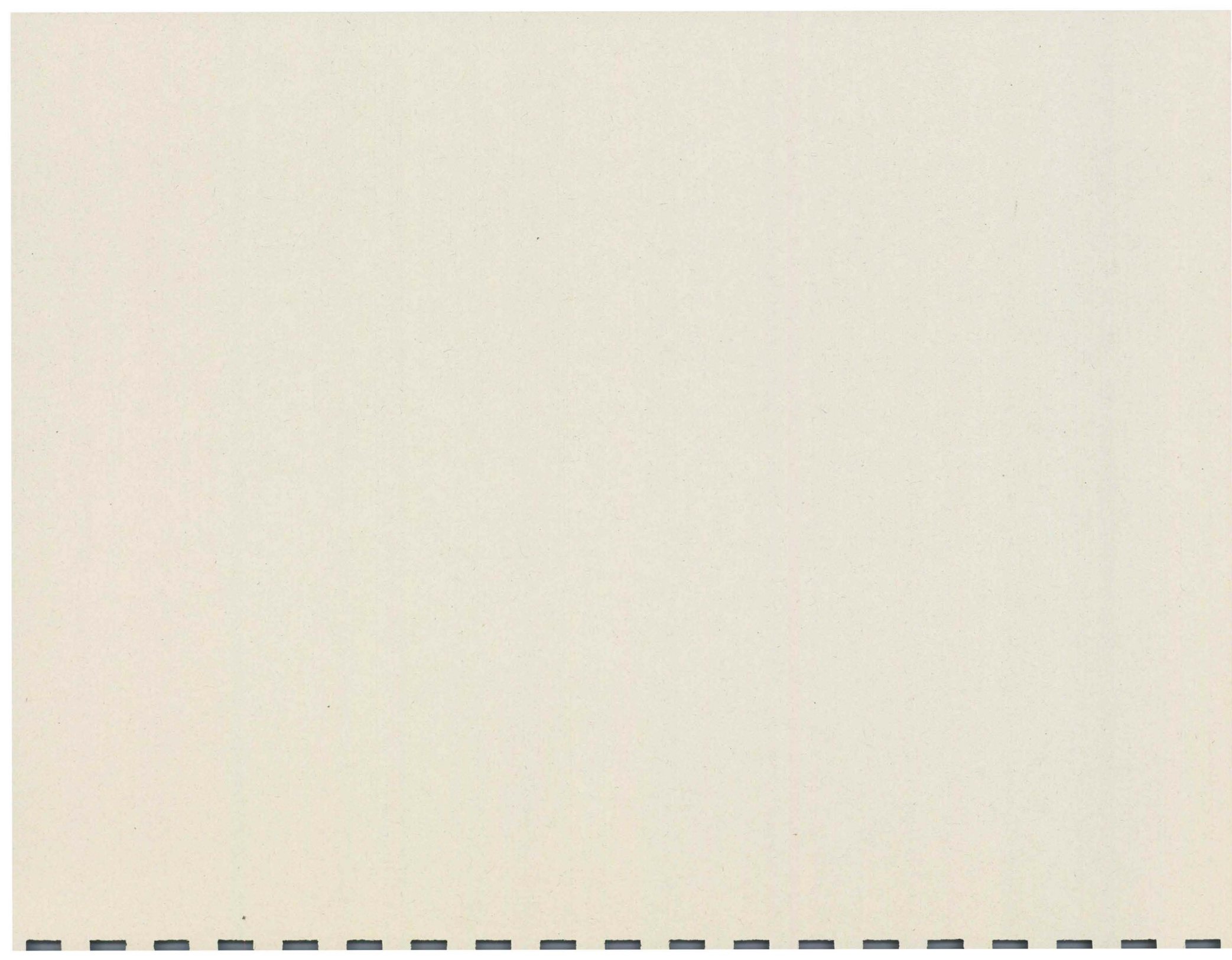
Education  
Employment  
Leisure Activities  
Early Intervention  
Financial Support Services  
Prevention  
Residential Services  
Age groups served  
Licensing/Accreditation  
Area served

To learn more about IOWA COMPASS, contact:

IOWA COMPASS  
M104 Oakdale Hall  
Oakdale, Iowa 52319

Phone: 1-800-779-2001  
Toll free voice and TTY  
or  
(319)335-4324

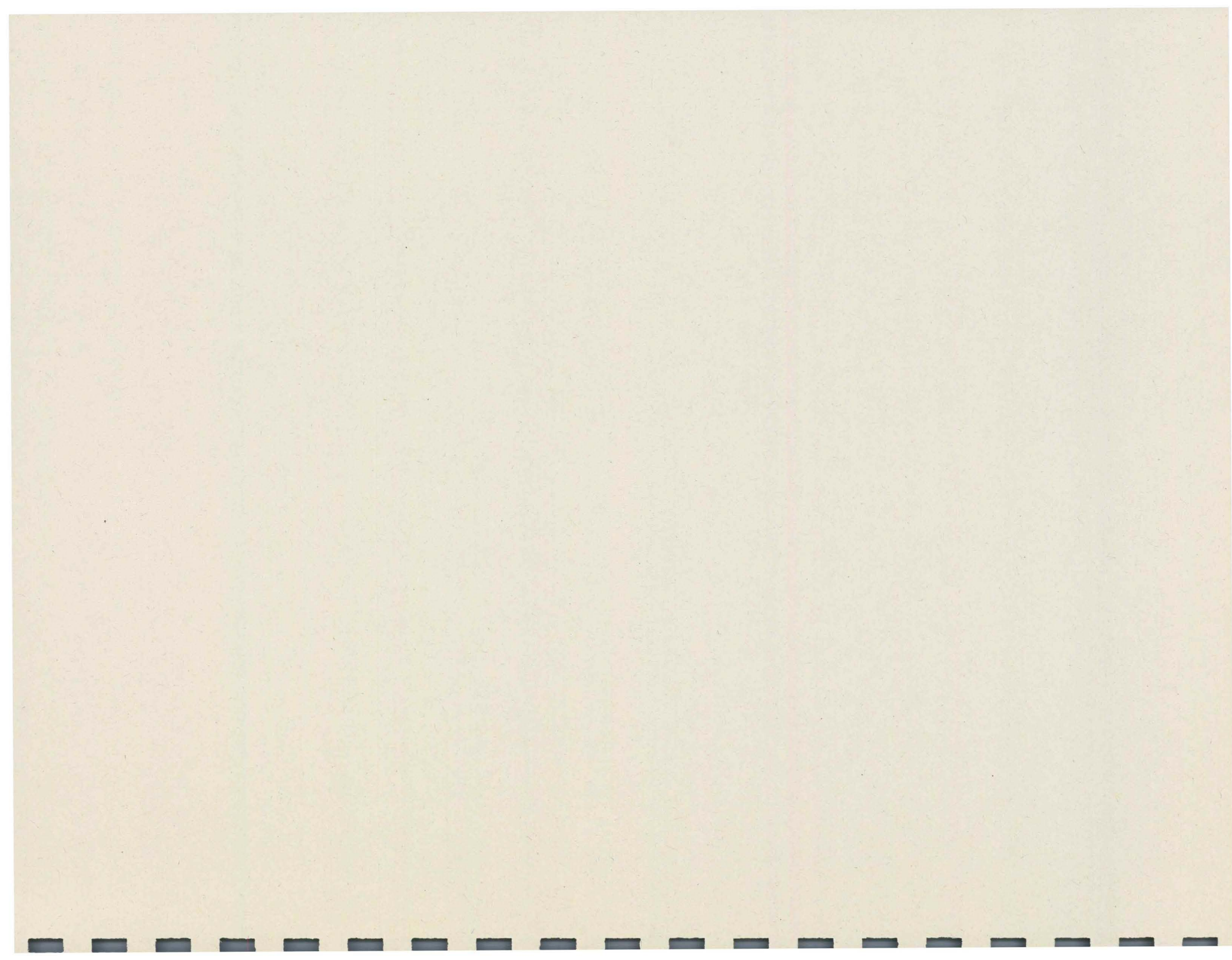






**ADDENDUM 2:**  
**MILD BRAIN INJURY**







## ADDENDUM: 2

### MILD BRAIN INJURY

Mild brain injury is commonly the result of a blow to the head or abrupt changes in direction. It may result in loss of consciousness followed by headache, blurred vision, irritability to light and noise, and dizziness.

Mild brain injury is a common problem and accounts for most of the brain trauma in the United States and the rest of the industrialized world. The majority of mild brain injuries in the United States are due to motor vehicle crashes (42 percent); falls (23 percent); assaults (14 percent); falls from bicycles (6 percent); sports and recreation activities (6 percent); and all other injuries (8 percent).

As in all brain injury, the force of the event may damage a local spot or it may be spread throughout the brain. The brain is the consistency of gelatin or custard. When the brain is struck with sufficient force, the brain rotates back and forth inside the skull, striking its hard and sharp bony ridges. Rotational forces may cause diffuse tearing in the brain. Often, no abnormality shows up on imaging studies or with a neurological examination. The injured individual also may not notice behavior changes until a task challenges the area of the brain which has been damaged.

Whether the injury to the brain is focal or diffuse, the speed of information processing is slowed; the ability to handle multiple tasks is reduced; the ability to learn new information is more difficult; emotional control is disrupted; and the person is not able to integrate new ideas or communicate them efficiently. In addition, the person may experience blurred-vision, loss of smell, headache, nausea, irritability to light and noise, and fatigue with an increased need for rest.

Children experience the same symptoms from mild brain injury as adults. Children, however, differ from adults by being more prone to swelling of the brain even with no loss of consciousness. Symptoms in children with mild brain injury are also amnesia, irritability, headaches, fatigue, etc. They too experience difficulties when performing higher level thinking, physical coordination and controlling emotions. On occasion, they will experience seizures.

The majority of injuries in motor vehicle crashes occur in males from 15 to 24 years of age. Data shows that men who are injured are most often single and from lower socioeconomic groups. Many have had problems with alcohol or drug abuse. (Third Injury Prevention Conference p. 504) Injury from assaults follows a similar pattern. Falls occur most often to individuals who are under 5 and over 65. In sports and recreation activities the female injuries peak in the 5-9 age group and males in the 10-14 age group. (Levin pp. 12-13)

Mild head injuries in sports present a different problem. Incidence and outcome of sports-related traumas has not been adequately investigated. Sports such as boxing and football both involve blows to the head. A syndrome which is characterized by mild confusion and tremors of the upper extremities and head is a result of numerous knockouts. However, amateur boxers are not likely to have head injuries. (Levin, pp 258-262) This may be the result of wearing protective headgear.



Mild head injuries in football have only recently been considered a problem. Many football players have had one or more concussions during their career. Some team physicians advise players to discontinue participation once they have received three cerebral concussions. (Levin, pp 263-264).

Other sports in which mild head injury can occur include: equestrian activities such as polo or racing and winter sports such as skiing. Head injuries in sports such as ice hockey are likely to be more serious. (Levin, pp 258-265).

A study done in San Diego County, California in 1981 provided the following medical breakdown for mild head injury: 80 percent were commonly diagnosed as a concussion accompanied occasionally by a fracture. The remaining diagnoses were intracranial, contusion or hemorrhage. (Levin, p 14). A mild head injury does not usually present with coma, as defined by the Glasgow Coma Scale (GCS), a checklist that evaluates motor or verbal responses, and whether the patient opens his eyes. Often acute injury to other parts of the body overshadows concerns about the presence of a mild brain injury. (Levin, p 15).

A mild head injury may result in depression and loss of confidence. Even the use of specialized neurophysiological tests may be unable to document cognitive losses after a few weeks have elapsed.

Life circumstances and the type of mild head injury affects how the individual will adjust to any changes in ability to function. Some individuals will turn certain tasks over to someone else. Other abilities that were lost may not be required in daily functioning. Most important for the patient is support from family and friends. Accepting what is lost enables the person to rebuild a positive sense of self and use the remaining skills and abilities.

In summary, mild brain injury is a significant problem that has not been adequately addressed. Mild trauma has the potential to affect behavior in subtle ways. The possibility of a mild brain injury should be routinely considered when a differential diagnosis is being provided by health care professionals. Some major trauma centers in Iowa are beginning comprehensive follow-up and research projects for persons with mild head injury. The staff involved in the projects have been properly trained to ensure appropriate treatment and documentation.



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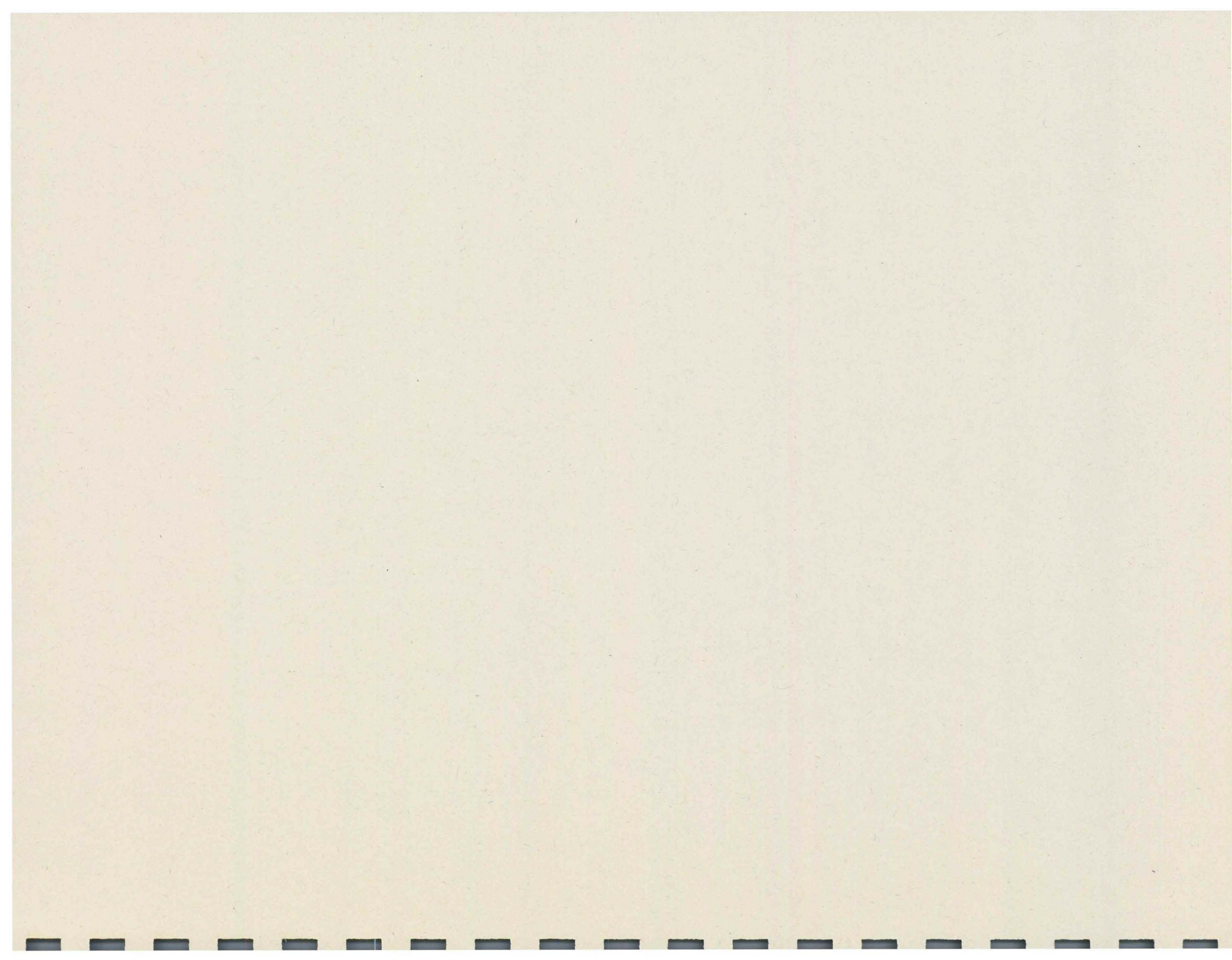
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