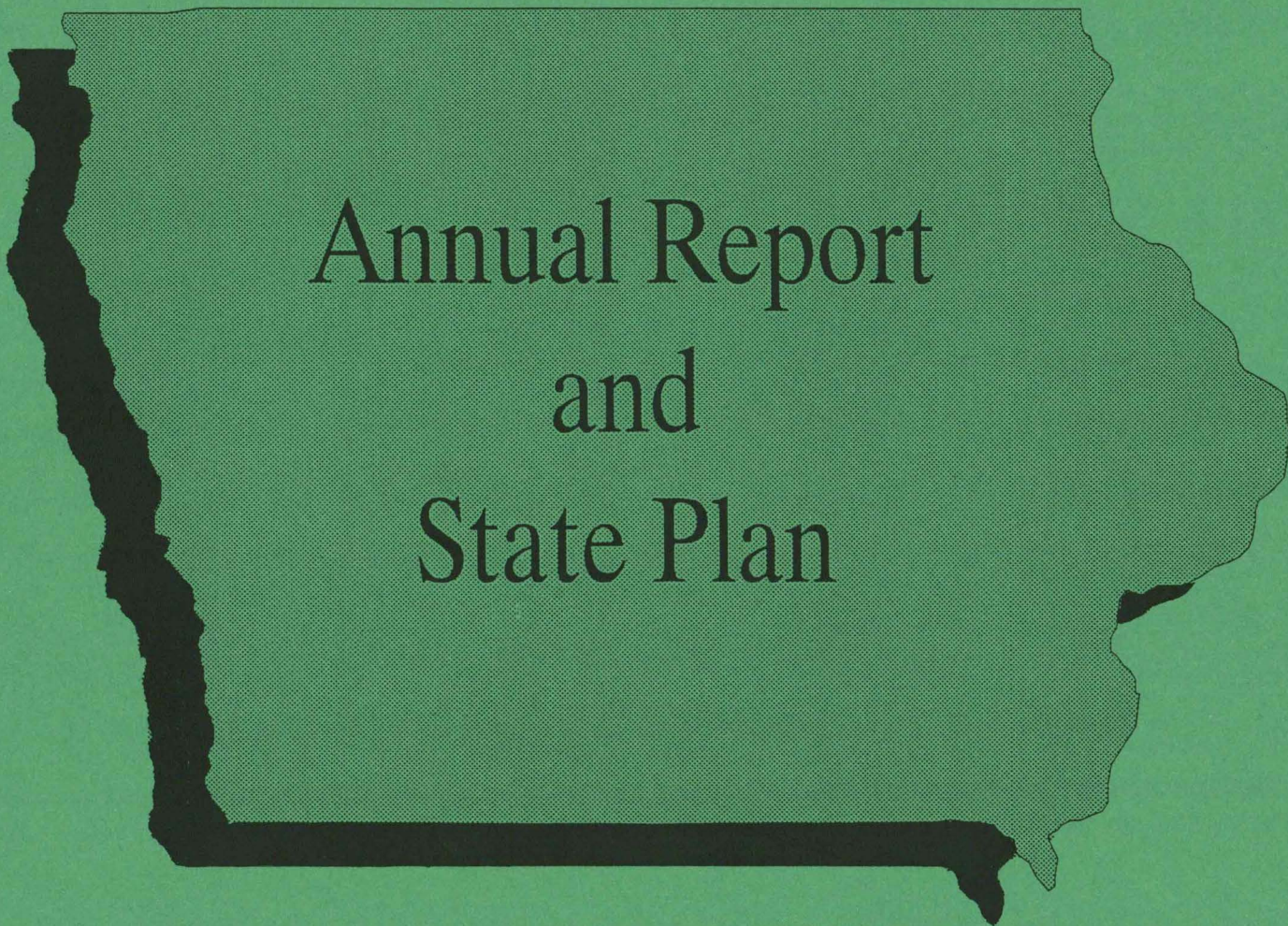


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Iowa Advisory Council on  
Head Injury

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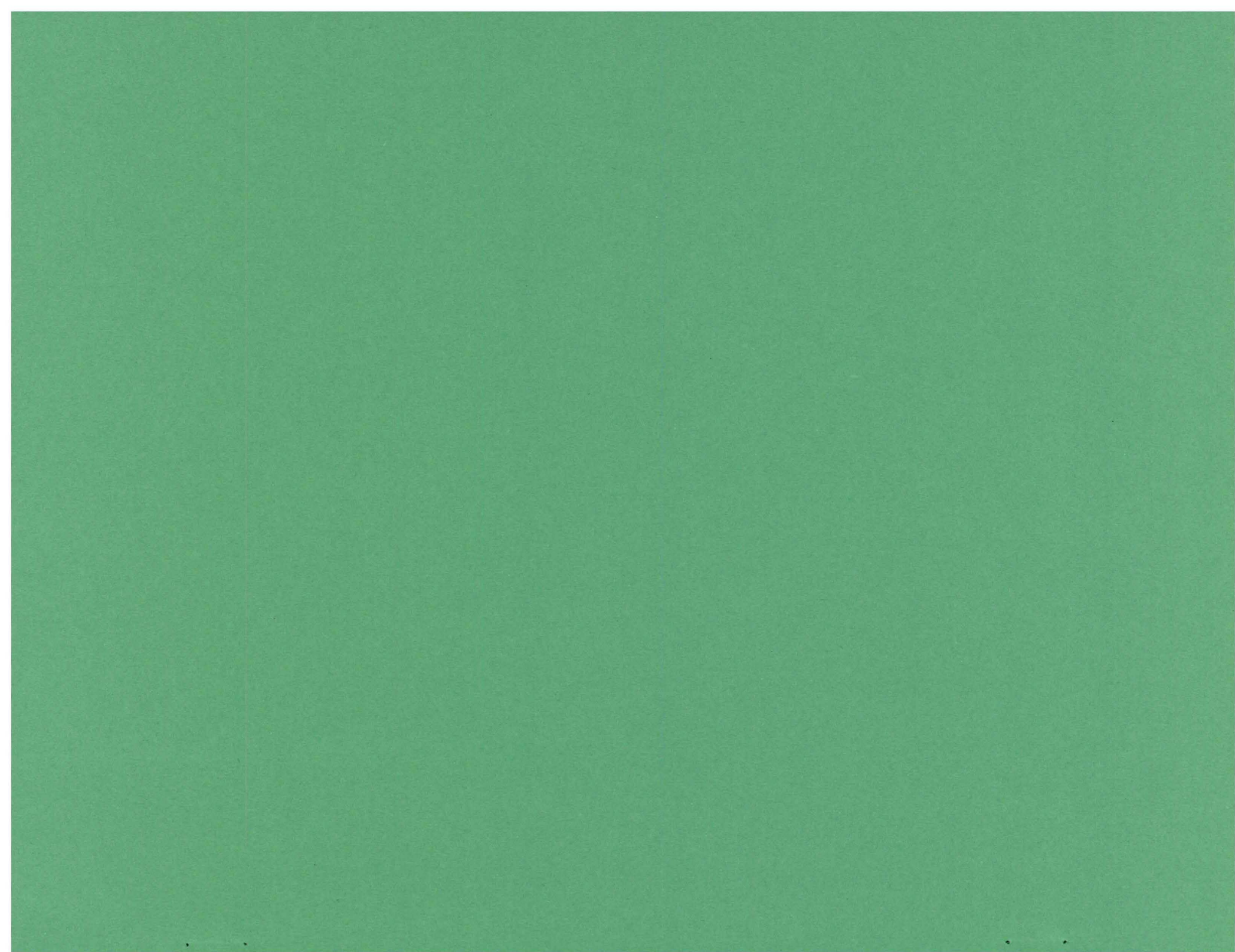
Annual Report  
and  
State Plan

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1992

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**IOWA ADVISORY COUNCIL  
ON HEAD INJURIES**

**ANNUAL REPORT  
AND  
STATE PLAN**

**April, 1993**







TERRY E. BRANSTAD, GOVERNOR

DEPARTMENT OF PUBLIC HEALTH  
CHRISTOPHER G. ATCHISON, DIRECTOR

April 28, 1993

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

Dear Governor Branstad and Members of the General Assembly:

On behalf of the Iowa Advisory Council on Head Injuries it is my pleasure to forward to you the Annual Report summarizing the activities of the Council as required by Iowa Code. It should be noted that the staff position supporting council activities was vacant for approximately nine months. This had an adverse effect on both Council operation and the timeliness of this report.

This report contains a Service Delivery State Plan which outlines the goals and objectives of the Council. The elements addressed are as follows:

1. Prevention
2. Central Registry for Brain and Spinal Cord Injuries
3. Service Delivery Plan

We wish to thank you for your continued support of Iowans who have sustained brain injuries and look forward to working with you in the coming year.

Please do not hesitate to contact the Council if we may be of further assistance to you.

Sincerely,

  
Jo Ann Kramer  
Chairperson





## Voting Members

**Jo Ann C. Kramer, MA**, Waterloo, is 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.

**Patricia L. McCollom, RN, MS, CRRN, CIRS**, Johnston, is the vice chairperson of the Council, and is the chairperson for the Service Provision Task Force. She is the President and Senior Rehabilitation Consultant for Management Consulting and Rehabilitation Service, Inc. and is a board member emeritus of the Iowa Head Injury Association - Central Area Group.

**John D. Bayless, Ph.D.**, Cedar Rapids, is the secretary of the Council, and is on the Service Provision Task Force. He is a Neuropsychologist providing consulting and rehabilitation counseling services to brain injury, neurology and psychiatry units in several Iowa hospitals, and the Vice-President of the Iowa Head Injury Association - East Central Group.

**Julie Davis**, Sioux City is on the Service Provision Task Force. She is employed by Social Security Administration. She is active in providing awareness of programs available for disabled children and adults.

**Josephine Gruhn**, Spirit Lake, is on the Service Provision Task Force. She is a former member of the House of Representatives.

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

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

**Karen A. Johnson**, Davenport, is a IHIA member for 7 years; Board member for 4 years; local support member for 6 years; and Chair for 4 years. She has two family members who have sustained traumatic brain injuries.

**Clark Lane**, Humboldt, is a Life Insurance Agent. He has a son who has sustained a traumatic brain injury.

**John May, M.D.**, Des Moines, is the Medical Director of Blue Cross/Blue Shield of Iowa.

**Jeffrey S. Thomas**, Spencer, is a school psychologist for Lakeland Area Agency and team leader for AEA 3 Head Injury Resource team.

**Marvin L. Tooman, Ed.D.**, Ankeny, is on the Service Provision Task Force. He is the Chief Executive Officer of On With Life, inc. He is a board member of the Iowa Head Injury Association - Central Area Group.

**Carol A. Watson, Ph.D.**, Iowa City, is chairperson of the Prevention Task Force. She is the Vice President of Patient Care Services of Mercy Medical Center in Cedar Rapids. She is the Director of Prevention for the Iowa Head Injury Association, and was appointed to serve on the Prevention of Disabilities Policy Council.



**Albert F. Wiuff**, Ankeny, is on the Prevention Task Force. He is a General Contractor and is President of the Elview Company. He has a daughter who had a brain tumor.

## **Ex - Officio Members**

**Christopher Atchison**, Des Moines, is on the Prevention Task Force. He is the Director of the Iowa Department of Public Health.

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

**William Lepley**, Des Moines, is on the Prevention Task Force. He is the Director of the Iowa Department of Education.

**David Lyons**, Des Moines, is on the Service Provision Task Force. He is the Commissioner of the Insurance Division within the Iowa Department of Commerce.

**Chuck Palmer**, Des Moines, is on the Service Provision Task Force. He is the Director of the Iowa Department of Human Services.

**Craig Slayton**, Des Moines, is on the Prevention Task Force. He is the Director of the Iowa Department for the Blind.

**Jerry Starkweather**, Des Moines, is on the Service Provision Task Force. He is the Administrator of the Division of Vocational Rehabilitation within the Iowa Department of Education.

**Frank Vance**, Des Moines, is on the Prevention Task Force. He is the Chief of the Bureau of Special Education within the Iowa Department of Education.

## **Ex - Officio Representatives**

**Larry Allen**, Altoona, is on the Service Provision Task Force. He is a Management Analyst in the Division of Mental Health/Mental Retardation/Developmental Disabilities in the Iowa Department of Human Services.

**Ruth Burrows**, Des Moines, is on the Service Provision Task Force. She is an Assistant Chief in the Client Services Bureau of the Division of Vocational Rehabilitation within the Iowa Department of Education. She is a board member of the Iowa Head Injury Association.

**Roger Chapman**, Des Moines, is on the Prevention Task Force. He is the Program Manager for the Disability and Injury Prevention Program in the Division of Health Protection within the Iowa Department of Public Health.

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

**Steve Maurer**, Des Moines, is on the Prevention Task Force. He is a Consultant for the Severely and Profoundly Handicapped for the Bureau of Special Education within the Iowa Department of Education.



**Dan Winegarden**, Des Moines, is on the Service Provision Task Force. He is the First Deputy Commissioner for the Division of Insurance within the Iowa Department of Commerce.

## **Staff**

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





## Table of Contents

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### **ANNUAL REPORT**

Overview.....	2
Definition.....	3
Introduction.....	4
Council Accomplishments.....	5
Task Force Reports.....	6

### **SERVICE DELIVERY STATE PLAN**

Essential Component I: Prevention.....	7
Essential Component II: Central Registry for Brain and Spinal Cord Injuries.....	13
Essential Component III: Service Delivery .....	17

### **APPENDICES .....**

Appendix A-I: Charts.....	21
Appendix J: Model Service Delivery System .....	22

.....

### **ADDENDUMS**

Addendum 1: Resources.....	23
Addendum 2: Mild Brain Injury.....	29





## 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 which 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:

- 8,000 Iowans sustain a head injury with 1,700 of those suffering moderate to severe disabilities;
- majority of victims are male between the ages of 15-24;
- brain injury is the leading cause of death for Americans under the age of 34;
- approximately 2,311 school-aged children in Iowa sustained traumatic head injuries; 656 of these cases were serious enough to require hospitalizations;
- every person has a 1 in 10 chance of suffering a significant head injury;
- motor vehicle crashes are the leading cause of TBI nationwide;
- the cost for one person with a severe head injury is estimated at \$4.1 million according to American Re-Insurance Company. This figure is based on the average brain injury occurring at age 26 and includes the direct expense of medical treatment and indirect costs of rehabilitation and support services, and the person's lost income. It doesn't include pain, suffering, or lost quality of life;
- falls account for approximately 40% of the injuries reported in Iowa;
- nationally an estimated 70,000 people a year incur moderate-to-severe head injuries with children and young adults disproportionately affected.

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, disabled 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 future 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, as outlined in Iowa Code 135.22.

### Iowa Code 135.22

"brain injury" means clinically evident brain damage or spinal cord injury resulting directly or indirectly from trauma, infection, anoxia, or vascular lesions not primarily related to degenerative or aging processes, 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 which leads to additional brain damage. Localized damage may also occur with bruising or tearing of the brain tissue.

Persons with a head injury commonly experience deficits in one or all of 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.



## 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.

The mission of the Council is to 1) study the needs of survivors of head injury and their families, 2) promote and implement injury prevention strategies, 3) make recommendations regarding the planning, development, and administration of a comprehensive statewide service delivery system.

Governor Branstad appointed 10 voting members and seven ex-officio members to the Council. The members of the Council include survivors of head injury and their families, representatives of industry, labor, business, and agriculture, representatives of state and local government agencies administering medical, mental health, vocational rehabilitation, education, health, public safety, vocational education, and insurance programs, and other interested professionals and organizations.

The Council meets quarterly to make recommendations regarding funding, legislative initiatives, prevention, accessing the appropriate existing programs where professionals are 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 Council decided to change the existing format of the state plan to include action plans and objectives based on annual goals. This revision enables the Council to plan and evaluate progress based on the immediate needs while maintaining insight into the future challenges.



## COUNCIL ACCOMPLISHMENTS

### The Council:

- 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 attempt 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 and the Prevention of Disability Policy Council.
- 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 of Iowa, by:

- \* Reducing the length of acute hospital stay for persons with head injuries
- \* Preventing the State of Iowa 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. The Council is collecting data on number of people being served and the amount of dollars saved through this agreement. This system could save as much as \$250,000 as documented by an actual study.



- Advocated for Iowa motorcyclists to universally wear motorcycle helmets by supporting the Iowa Head Injury Association in efforts for 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.
- 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 are still being completed and will be 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.
- Updated the Council's brochure to reflect programmatic and legislative changes.

## **COUNCIL TASK FORCES**

### **Prevention**

The Prevention Task Force of the Advisory Council on Head Injuries has focused the past year on coordinating its efforts with the Prevention of Disabilities Policy Council and the Iowa SAFE KIDS campaign of the Department of Public Health. In addition, the Prevention Task Force has examined additional legislative actions needed which would support prevention endeavors. Universal helmet legislation was identified as the priority legislation. The Task Force members worked with staff from the Central Registry for Brain and Spinal Cord Injury to refine the report format.

### **Service Provision**

The Service Provision Task Force conducted a preliminary statewide survey to ascertain availability and to locate injury programs and providers. The results of this survey will enable the Council to conduct an in-depth survey of programs offering head injury services and identify what specifically is available.

A family survey was conducted, by the Service Provision Task Force, in order to better understand families' satisfaction with services received.





## **Essential Component I**

*Prevention of Primary and Secondary Disabilities  
Related to Head Injury*

### **Key Issues**

*Educate the public on the effects of brain injury.*

*Reinforce Education Continually.*

*Advocate for legislative and administrative laws that protect Iowans from injury.*

*Promote passive interventions.*

*Collect data for Effective Prevention and Intervention Strategies.*

*Identify funds for injury prevention and interventions strategies.*





## PREVENTION

Based on injury demographics, it is apparent that the incidence of head injury can be greatly reduced through prevention activities. In Iowa, of those hospitalized and treated in an emergency room, 40% are related to falls and 30% of all head injuries are caused by automobile crashes in 1991. 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. Such "accidents" 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 risk to alter their behavior.
2. Legislative - Require individual behavior change by law or administrative rule.
3. Passive - Provide automatic protection by product and environment design.

### Overview:

In 1983, Congress enacted a law authorizing the Secretary of the U.S. Department of Transportation to request a study on trauma/injury by the National Academy of Sciences. The committee issued a report in 1985, "Injury in America: A Continuing Health Problem." One of the findings of the committee was the lack of data necessary for the study of the epidemiology of most injuries which includes traumatic brain injury. This was true in Iowa until the Central Registry for Brain and Spinal Cord Injuries was established in July 1987. Systematic data collection is essential for planning and evaluating prevention programs.

**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. Falls tend to be bimodal in nature, occurring to the very young and the very old. Knowledge of these varied circumstances is limited in part by the International Classification of Disease (ICD-9) codes which do not provide detailed information. 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 be taken in identifying potential prevention measures for falls is to gain more detailed insight into the circumstances of their occurrence. To date, no comprehensive prevention efforts outside of institutional settings have been identified within the state of Iowa to deal with the problem of injuries resulting from falls.

**Motor Vehicles.** Motor vehicles are the second leading cause of 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.

**Helmet Usage.** 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 laws requiring helmet use. Motorcyclists' deaths have been reduced by about 30% in states with helmet laws. Iowa is one of the few states where the helmet law has been repealed (1976) with a subsequent rise in motorcycle deaths experienced in the first three years following repeal. The number of fatalities associated with motorcycle crashes has decreased since a high of 89 in 1979 to 37 in 1990. However, this is thought to be due to fewer registered motorcycles and fewer miles ridden.

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 (ATVs) 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 ATVs injuries and an alarming number of deaths, most caused by massive brain and spinal cord injuries. The number of reported ATV injuries is an underestimation of the true figures. There is not an ICD-9 code that exists exclusively for ATVs so they cannot be identified in hospital discharge data or death certificates. There are no regulations in Iowa for ATVs 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 ATVs, which have serious design problems. The popularity of ATVs among young children has greatly compounded the consequences of using these inherently dangerous vehicles.



**Teens: 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 begin driving. The peak age for motorcycle fatalities is slightly higher (25-34 years old) than for automobiles. In states such as New Jersey where the age of licensee is 17, motor vehicle occupant death rates are lower for 16-years-old than in states where the driving age is 16. Furthermore, there is no compensating effect with unusually high rates for 17 year-old drivers when licensing is postponed for a year. Apparently, the delaying the issuing of licenses results in a net savings of teenage lives. An innovative risk reducing measure has been successfully implemented in New York, Pennsylvania, Louisiana, and Maryland where 16 year-old drivers are limited to daytime and early evening driving. Curfews prohibit night-time driving in these states when a disproportionate number of fatal crashes occur. Teenagers do only 20% of their driving at night, but more than 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 among those least likely to wear safety belts, yet most likely to be involved in a crash. 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, so forth. 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.

## **PREVENTION ACTION PLAN 1993**

- **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, in particular their Traumatic Injury Prevention Strategies program (TIPS/THINK FIRST) and legislation issues, by providing data and technical assistance as requested.
  4. Maintain ongoing involvement with Iowa SAFE KIDS Coalition to coordinate efforts by attending regular meetings.
- **Establish a resource library with literature and audio-visual materials to assist in dissemination of information to the public**
    1. Maintain an ongoing collection of current informational materials on Traumatic Brain Injury.
    2. Publicize the availability of material by submitting five articles in professional journals or newsletters and three presentations to local Traumatic Brain Injury support groups or in combination with other injury prevention focused activities such as Iowa Safe Kids Coalition, Project Lift, and health fairs, by December 30, 1993.
    3. Meet with the Iowa Head Injury Association (IHIA), semi-annually to review materials in order to provide consistency of Traumatic Brain Injury materials.
    4. Respond to requests for information within five working days.
  - **Develop and support a legislative agenda for 1994 which addresses the following:**
    1. Lowering the legal blood alcohol level to .08.
    2. Effective motorcycle legislation that conforms to federal recommendations.
    3. Change 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. Meet with a Department of Education representative by July 15, 1993, to discuss additional funds for low-income adolescents who are taking driver education in summer school to increase enrollment by diminishing costs, thereby increasing accessibility.
    6. Identify a key legislator who can serve as an advocate for the council's legislative agenda by November 30, 1993.
    7. Provide materials for the identified legislator as needed to support legislative initiatives.

- **Develop programs to promote head injury awareness through activities during "National Head Injury Awareness Month."**
  1. Initiate a Gubernatorial Proclamation signing with the Head Injury Council.
  2. Develop two news releases and/or public service announcements during awareness week in October 1993.
- **Identify funds to develop and implement an intervention strategy focused on reducing injuries due to falls.**
  1. Contact potential governmental resources such as Centers for Disease Control, Maternal and Child Health funds (MCH), and civic organizations by September 30, 1993.
  2. Utilize Iowa data from the Central Registry for Brain and Spinal Cord Injuries to determine a population and geographic area to pilot by December 1993.





## **Essential Component II**

### *Central Registry for Brain and Spinal Cord Injuries*

#### **Key Issues**

*Improve the uniformity of information reported to the Registry on cause, type, and severity.*

*Improve compliance to the Registry.*

*Expand the information collected on the Registry's reporting form.*

*Increase the number of sources reporting to the Registry.*

*Collaborate with other agencies that collect injury data.*

*Educate and train personnel who are responsible for reporting injuries.*

*Utilize data to persuade policy makers to make informed decisions on safety issues.*

*Provide useful feedback to reporting sources.*





## BRAIN AND SPINAL CORD REPORTING

### 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 (CRBSCI) 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. Injuries are also the leading cause of short and long term disability and disproportionately affect children and young adults in the United States. Data is critical for the development of effective interventions. To assist in the development of brain and spinal cord injury prevention programs, Iowa law requires health care providers to report incidents of injury to the Central Registry for Brain and Spinal Cord Injuries at the Department of Public Health. Reporting must be done within 45 days of discharge from the hospital. This information also facilitates the identification of appropriate rehabilitation services and community support programs lacking in Iowa.

Injuries which must be reported are defined in the Code of Iowa 135.22 as "clinically evident brain damage or spinal cord injury resulting directly or indirectly from trauma, infection, anoxia or vascular lesions (e.g., cancers of the central nervous system, strokes, etc.) not primarily related to degenerative or aging processes, which temporarily or permanently impairs a person's physical or cognitive functions."

Standardizing the coding system will promote prevention and intervention by identifying patterns of injury, injury severity, evaluating strategies, and planning for future injury controls. For calendar year 1993 the Registry will include questions on automatic protection devices (seat belts, and air bags) and helmets, source of payment and where hospitalized patients go after discharge.

The E-Code (cause of injury) for this report is categorized as follows:

<b>Motor Vehicles:</b>	All persons in motor vehicles used on highways, motorcycles/mopeds, and pedestrians injured.
<b>All bicycles:</b>	Falls from bicycles/tricycles and pedal cyclists injured by motor vehicles.
<b>Falls:</b>	Falls from buildings, downstairs, slipping, tripping, etc. Does not include diving or sports.
<b>Gunshot:</b>	Injuries from gunshots in all circumstances.



<b>Assault:</b>	Any injury supposedly inflicted by someone else--fights, poisoning, drowning, firearms, child battering, etc.
<b>Sports:</b>	Injuries due to diving, falls in sports, struck by bats, balls, etc.
<b>Unintentional:</b>	Undetermined whether injury was accidentally or purposely inflicted.
<b>Miscellaneous:</b>	Injuries involving railway, aircraft, watercraft, roller skates, struck by falling objects and other objects, etc.

The report must contain the name, age, residence, date, and cause of injury, and the Glasgow Coma Scale (if available). Other information such as race, cause of injury are being discussed as additions to the form to assist in identification and in prevention strategies. All hospitals in the state of Iowa have been supplied Registry reporting forms. Rehabilitation facilities are also being targeted for another source to collect data.

The submission of complete and accurate registry data allows injury prevention specialists to target high risk groups, initiate prevention activities, and evaluate the effectiveness of prevention strategies. During the past year, Registry data has been used for prevention programs such as bicycle safety, playground safety, child-passenger restraint programs, and motorcycle helmet legislation.

Hospital compliance has increased to 93% in 1992 from 83% in 1991 and 60% in 1990. Increased participation and compliance will improve the quality of data and enhance development of other prevention programs specific to Iowa's population (Appendix A).

## INCIDENCE

### Background:

Based on national estimates, Iowans can expect 5,000-10,000 brain injuries serious enough that medical treatment is needed. Of the Iowans who are brain injured each year, it is estimated that:

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

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 annual and direct costs of persons sustaining brain and spinal cord injuries in Iowa are estimated to be between \$350 million to \$400 million. Brain injuries account for approximately two-thirds of the injuries compared to spinal cord injuries.



## **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 1991, a total of 5,353 such injuries were reported (Appendix B).

Iowa follows the national trend with males experiencing 61% (2,677) of the traumatic brain injuries reported. Females experienced 39% (1,740) traumatic brain injuries, which continues last year's pattern (Appendices C and D).

"Falls" constitute the majority of the injuries, especially for children under 5 years old and females over the age of 65. Children under 5 years old account for 489 of the reported falls, and females over age 65 represent 183 of the reported falls. There were 1,756 falls reported during calendar year 1991 (Appendix E).

Motor vehicle injuries are the second leading cause of traumatic brain injury and include motor vehicles, motorcycles, and pedestrians. Of the 1,360 motor vehicle crashes, 247 involved injuries to females age 15-24, while 323 involved males age 15-24 (Appendices C, D, and E). Alcohol use is often associated with motor vehicle injuries.

"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 419 assaults reported, 284 injuries were to males and 135 were to females (Appendices E, F, and G).

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

## **CENTRAL REGISTRY'S ACTION PLAN FOR 1993**

- **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.
- **Identify areas of need for facilities and services for survivors of TBI and their families.**
  1. Analyze Registry data to determine specific geographic locations within the state of Iowa lacking in community-based programs.
  2. Provide appropriate recommendations to the Governor and legislators based on data analysis to be included in the next annual report.





## **Essential Component III**

### *The Development of a Statewide Service Delivery Plan*

#### **Key Issues**

*Plans of care developed by credentialed professionals in the speciality of traumatic brain injury.*

*Design programs that are client specific.*

*Full inclusion of families in program development for survivors of brain injuries.*

*Access available funds persons with brain injury.*

*Provide the support systems necessary for community reentry.*

*Ascribe to standards established by professionals and/or accrediting groups.*

*Advocate for the appropriate use of professionals who meet the specific needs of clients*

*Advocate for the development of quality community-based programs to meet the needs of this special population.*

*Provide continuous appropriate support and follow-up during transitional periods.*







## SERVICE DELIVERY PLAN

### Background:

Medical technology has advanced significantly resulting in hundreds of Iowans with brain injury surviving and returning to the community. National data indicates that 60,000 to 80,000 moderate to severe brain injuries occur each year with an estimated cost of \$4.1 million per case. Mild head injuries which are not included in the numbers above account for the majority of brain trauma in the United States. Often going undiagnosed, these individuals are left to struggle with frustration, guilt, and feelings of worthlessness if they find they are not able to maintain their pre-injury performances. The numbers of all classifications of brain injuries are continuing to increase with a disproportionate amount occurring to our youth.

### Overview:

The escalating survival rate has resulted in a need for an increased use of existing services as well as creation of new services. Providing quality care for survivors of traumatic brain injury is challenging due to the diversity of their needs and few qualified professionals to serve this group. The services provided must be flexible and specifically designed for the individual. Each person will use the service delivery system differently. The major service areas in the delivery model include: Prevention; emergency medical and medical care; case management; residential; and community support services (Appendix J).

These services may be used by an individual in a variety of combinations. The client may go through each step, or may move from acute medical care into community integration, while others require extended periods of nursing care. Complexity of treatment makes it critical that their care plan be determined by a team, including credentialled professionals in the area of brain injury such as physiatrist, a physician who specializes in rehabilitation, and a certified registered rehabilitation nurse.

The consumers of the services must be given the opportunity to organize their lives in the "least restrictive" environment to encourage creativity, resourcefulness, and independence. In order to accomplish this "brain injury" needs to be included in the Department of Human Services budget to provide funding sources and access to existing appropriate programs in our state. Until this is completed the "brain injured" population will be discriminated against when seeking accessible, affordable, and appropriate care.

If our state moves forward based on recommendations from the task forces appointed to study service delivery to a community integration/community based focus for its human service system, programs and opportunities for individualizing those programs to meet the specific needs of those with traumatic brain injury will be served. Until that time, survivors of brain injury are left without the other array of services that other disability groups have been entitled to for many years. Those services include: 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 programs, transitional living, psychosocial counselling and support for independent living...all community re-entry services. Survivors of brain injury and their families need to be considered for funding and services in the Iowa Code similar to the other disabilities groups or identified and acknowledged in the Code as a separate group to ensure services.



While our ultimate goal is for the survivor to return to community living, it must be acknowledged that the level of functioning will vary because some individuals will need lifelong rehabilitative/habilitative services. This is a significant issue for families. The financial resources available to individuals with head injury may include coverage through Medicare/Medicaid, standard health insurance, health maintenance organizations(HMO), governmental health care programs, as well as insurance contracts. However, these resources are inadequate to cover the devastating costs associated with brain injuries and families are often left destitute.

To address this issue, we must look at the number of Iowans who are uninsured or underinsured. Many insurance policies do not begin to cover the catastrophic costs associated with brain injuries which leaves the injured person with inappropriate or no rehabilitation services. Cost effectiveness for programming will come about when credentialed and experienced staff are implementing and designing the care plan for survivors of brain injury. Along with the skilled professionals it is important to include the family as an integral part of the planning. Survivors achieve their maximum potential by proper placement and treatment following a brain injury.

The Council will continue to advocate for accessing appropriate health and human services for survivors of traumatic brain injuries in a cost-effective manner, and promote productive, independent lives for survivors of traumatic brain injury.

## **SERVICE DELIVERY ACTION PLAN 1993**

- **Develop a collaborative and informational network for data collection, program sharing, and outcome reporting.**
  1. Maintain active participation by Department of Human Services representative(s) in network development by attending a minimum of three Council meetings.
  2. Invite a minimum of four different providers to Council meetings.
  3. Request presentations from providers to promote Council members awareness for each meeting.
  4. Respond to and present to all requests for educational programming regarding service provision issues.
  5. Provide input to appropriate sources regarding service standard development.
- **Assist in the development and implementation of a Traumatic brain injury waiver in Iowa.**
  1. Investigate strategies and language used in medicaid waivers implemented in surrounding states, i.e.. Kansas, and Minnesota, by September 30,1993.
  2. Collect data from the Registry that supports the need for a waiver program in Iowa by December 31, 1993.

3. Identify a key legislator to support the waiver by August 31,1993.
4. Establish a stronger link with Department of Human Services (DHS) to encourage the development of the TBI waiver by ongoing communication.

■ **Coordinate traumatic brain injury service resource materials through Iowa Compass.**

1. Assist in the development of a service directory for survivors of brain injury and their families by reviewing the data base collected from Iowa Compass by December 31,1993.
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.





## APPENDICES A - I

### *Central Registry for Brain and Spinal Cord Injuries*

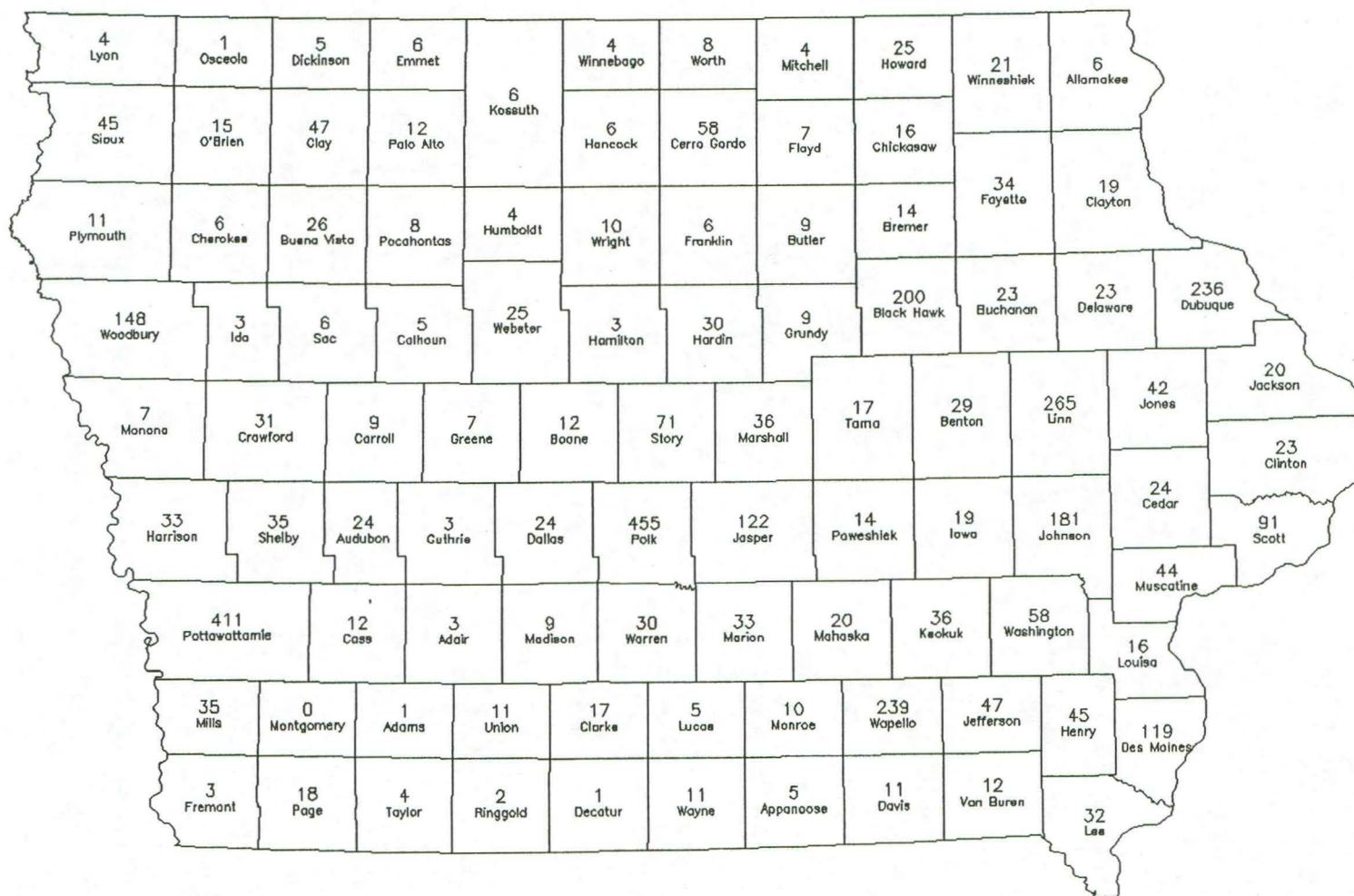
- A: Traumatic Brain Injuries-1991- Emergency room and Hospitalized
- B: All injuries-Emergency Room and Hospitalized
- C: Traumatic Brain Injuries treated in Emergency Room and Hospitalized by Cause of Injury and Age for Males-1991
- D: Traumatic Brain Injuries treated in Emergency Room and Hospitalized by Cause of Injury and Age for Females-1991
- E: Traumatic Brain Injury by Cause-1991-Emergency Room and Hospitalized
- F: Traumatic Brain Injuries treated in Emergency Room and Hospitalized-1991  
Alcohol-Related by Age and Cause
- G: Traumatic Brain Injuries/Alcohol-Related-1991- by Cause Treated in  
Emergency Rooms and Hospitalized
- H: Hospitalized Traumatic Brain Injuries by Cause of Injury and Age-1991
- I: Hospitalized Traumatic Brain Injuries-1991-By Cause





# CENTRAL REGISTRY FOR BRAIN AND SPINAL CORD INJURIES

## Traumatic Brain Injuries – 1991 Emergency Room and Hospitalized



With Iowa Residence	4,048
Without Iowa Residence	372
<b>TOTAL</b>	<b>4,420</b>





## Iowa Central Registry for Brain and Spinal Cord Injuries

All Injuries-Emergency Room and Hospitalized - 1991

<u>Primary Diagnosis</u>	<u>&lt;1</u>	<u>1-4</u>	<u>5-14</u>	<u>15-24</u>	<u>25-44</u>	<u>45-64</u>	<u>65+</u>	<u>Undetermined age &amp; sex</u>	<u>Total</u>
Traumatic Brain	97	530	743	1,182	1,076	388	400	18	4434
Traumatic Spinal Cord	2	2	18	87	144	66	110	6	435
Head & Neck	0	18	46	117	106	43	33	3	366
Anoxia	0	1	2	2	3	5	8	1	22
Infection	0	0	1	1	4	2	1	0	9
Vascular	1	0	0	3	14	30	0	1	49
Poisoning	0	1	1	3	8	5	1	0	19
Drowning & Suffocation	<u>0</u>	<u>4</u>	<u>1</u>	<u>3</u>	<u>7</u>	<u>0</u>	<u>4</u>	<u>0</u>	<u>19</u>
	100	556	812	1,398	1,362	539	557	29	5,353





## Iowa Central Registry for Brain and Spinal Cord Injuries

Traumatic Brain Injuries Treated in Emergency Room and Hospitalized by Cause of Injury and Age for Males - 1991

<u>Cause of Injury</u>	<u>&lt;1</u>	<u>1-4</u>	<u>5-14</u>	<u>15-24</u>	<u>25-44</u>	<u>45-64</u>	<u>65+</u>	<u>Total</u>
Motor Vehicle	4	17	56	293	233	49	31	683
Motorcycle	0	0	3	25	22	5	2	57
Pedestrian	1	3	19	5	5	0	2	35
All Bicycle	1	3	60	21	11	4	1	101
Falls	43	241	213	117	142	97	120	973
Gunshot	0	0	3	4	6	3	1	17
Assault	4	6	16	118	130	8	2	284
Sports	0	6	43	84	17	1	0	151
Undetermined Intent	1	6	7	9	15	6	3	47
Miscellaneous	<u>3</u>	<u>26</u>	<u>73</u>	<u>74</u>	<u>87</u>	<u>47</u>	<u>19</u>	<u>329</u>
Total	57	308	493	750	668	220	181	2,677

With Birth Date known  
4/22/93





## Iowa Central Registry for Brain and Spinal Cord Injuries

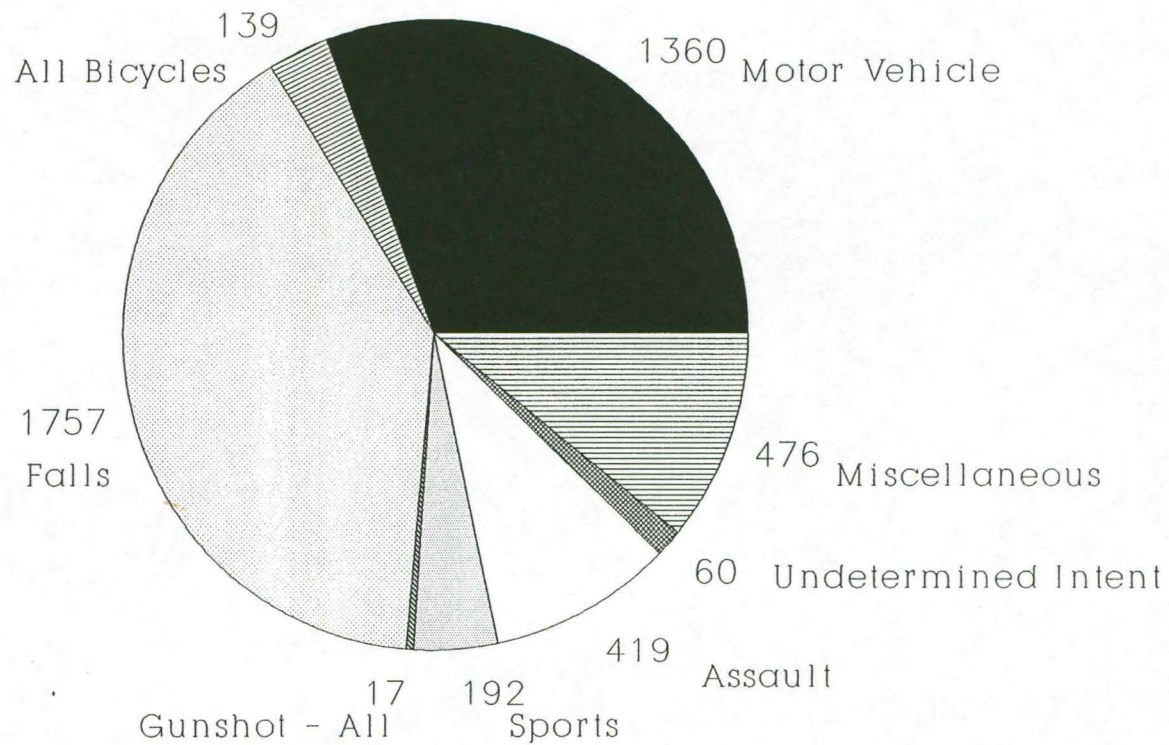
Traumatic Brain Injuries Treated in Emergency Room and Hospitalized by Cause of Injury and Age for Females - 1991

<u>Cause of Injury</u>	<u>&lt;1</u>	<u>1-4</u>	<u>5-14</u>	<u>15-24</u>	<u>25-44</u>	<u>45-64</u>	<u>65+</u>	<u>Total</u>
Motor Vehicle	7	15	40	243	165	63	30	563
Motorcycle	0	0	0	1	3	0	0	4
Pedestrian	0	2	6	3	0	1	4	16
All Bicycle	1	2	27	1	5	2	0	38
Falls	28	177	128	87	104	76	183	783
Gunshot	0	0	0	0	0	0	0	0
Assault	2	2	9	42	68	11	1	135
Sports	0	3	11	18	7	1	1	41
Undetermined Intent	0	1	2	3	4	1	2	13
Miscellaneous	<u>0</u>	<u>20</u>	<u>28</u>	<u>34</u>	<u>51</u>	<u>10</u>	<u>4</u>	<u>147</u>
Total	38	222	251	432	407	165	225	1,740





Central Registry for Brain and Spinal Cord Injuries  
Traumatic Brain Injuries by Cause - 1991 - ER & Hospitalized



N = 4,420 Birth Year 1875 to Present; Sex Known





## Iowa Central Registry for Brain and Spinal Cord Injuries

Traumatic Brain Injuries treated in Emergency Room and Hospitalized - 1991

Alcohol-related by Age and Cause\*

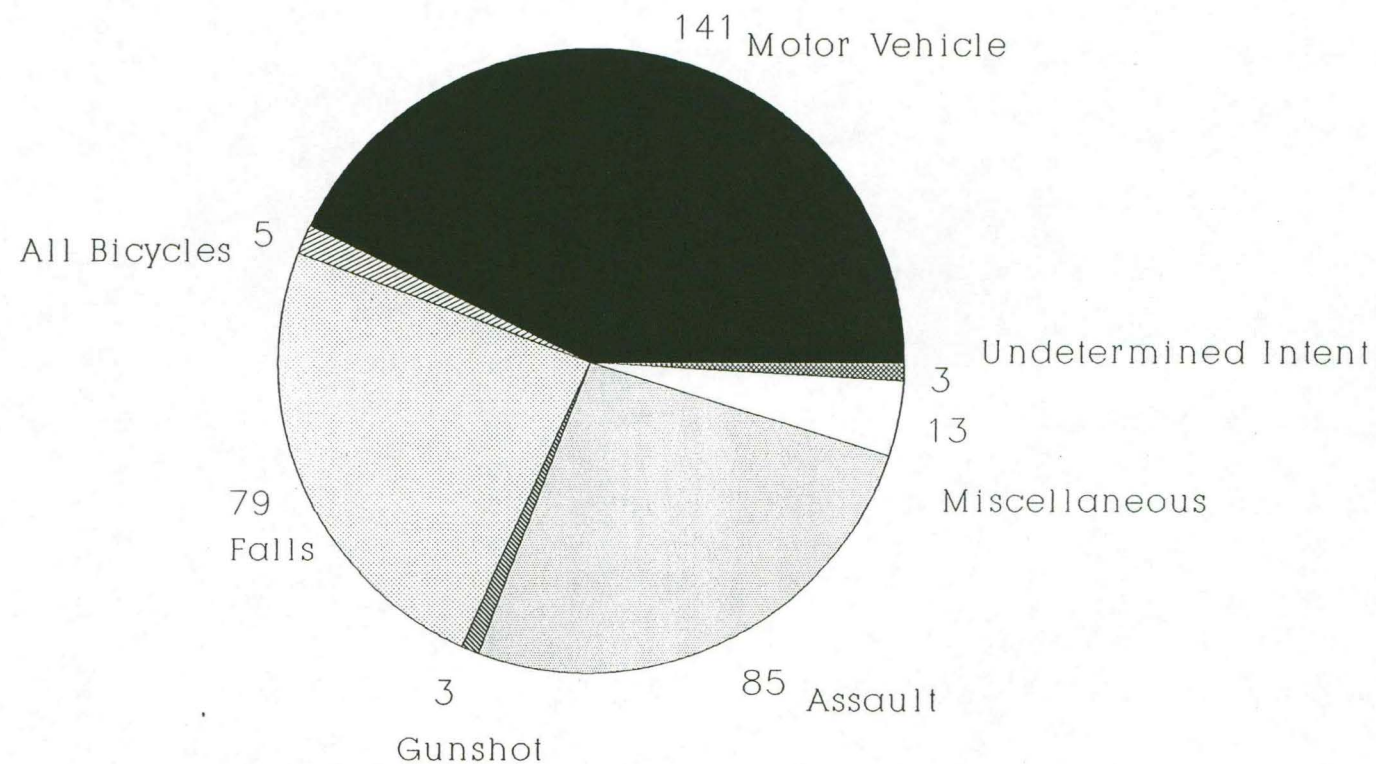
<u>Cause of Injury</u>	<u>15-24</u>	<u>25-44</u>	<u>45-64</u>	<u>65+</u>	<u>Total</u>
Motor Vehicle	60	63	3	1	127
Motorcycle	5	7	0	0	12
Pedestrian	1	1	0	0	2
All Bicycle	3	2	0	0	5
Falls	24	29	19	7	79
Gunshot	2	1	0	0	3
Assault	31	50	4	0	85
Undetermined Intent	2	1	0	0	3
Miscellaneous	<u>6</u>	<u>6</u>	<u>1</u>	<u>0</u>	<u>13</u>
Total	134	150	27	8	329

\* No Alcohol-Related Injuries 0-14 Years of Age with Birth Date and Sex known  
4/22/93





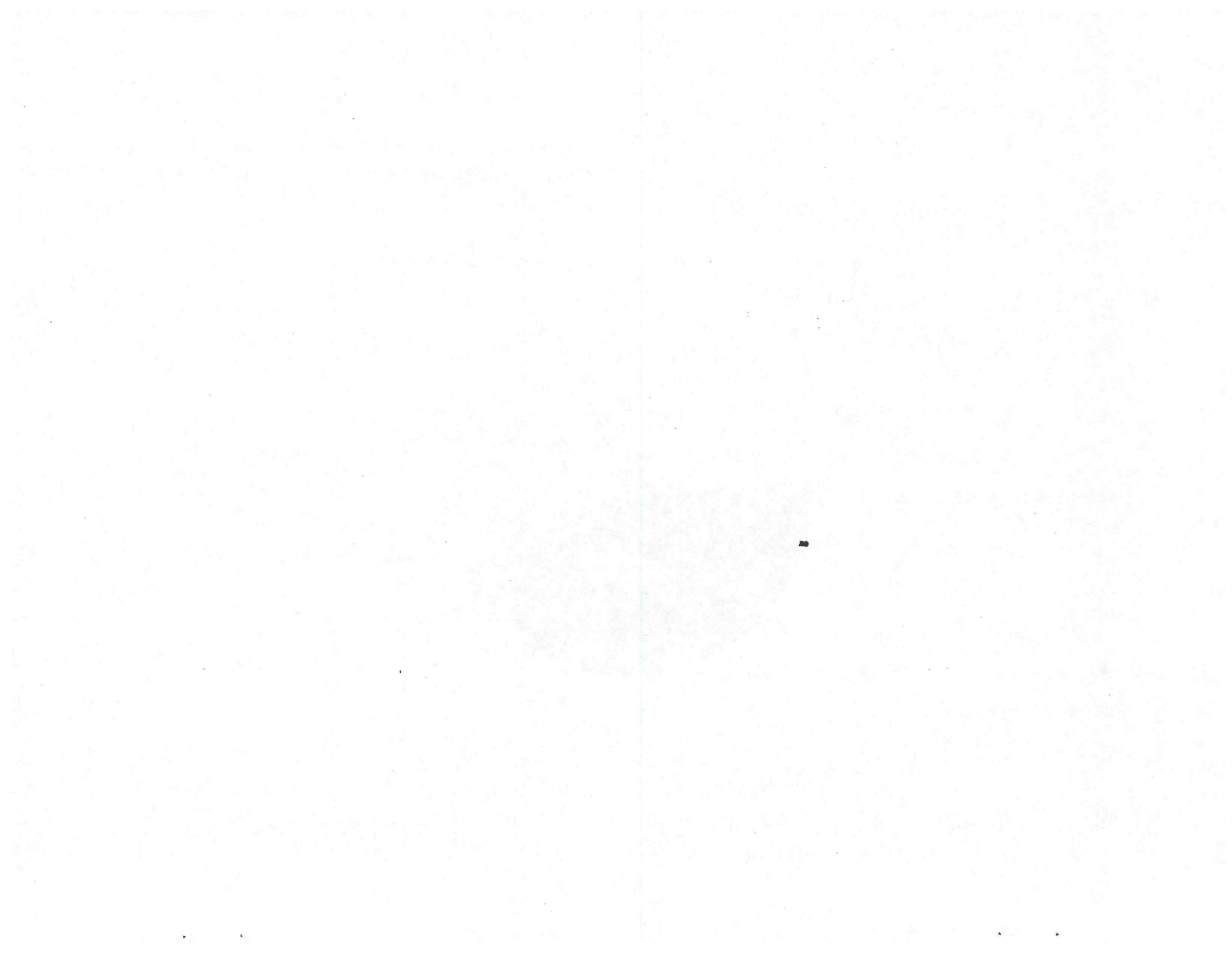
Central Registry for Brain and Spinal Cord Injuries  
Traumatic Brain Injuries/Alcohol-Related-1991 By Cause  
Treated in Emergency Rooms & Hospitalized



N = 329 With Sex Known; Birth Date Known

\* Alcohol not present in 0 - 14





## Iowa Central Registry for Brain and Spinal Cord Injuries

Hospitalized Traumatic Brain Injuries by Cause of Injury and Age - 1991

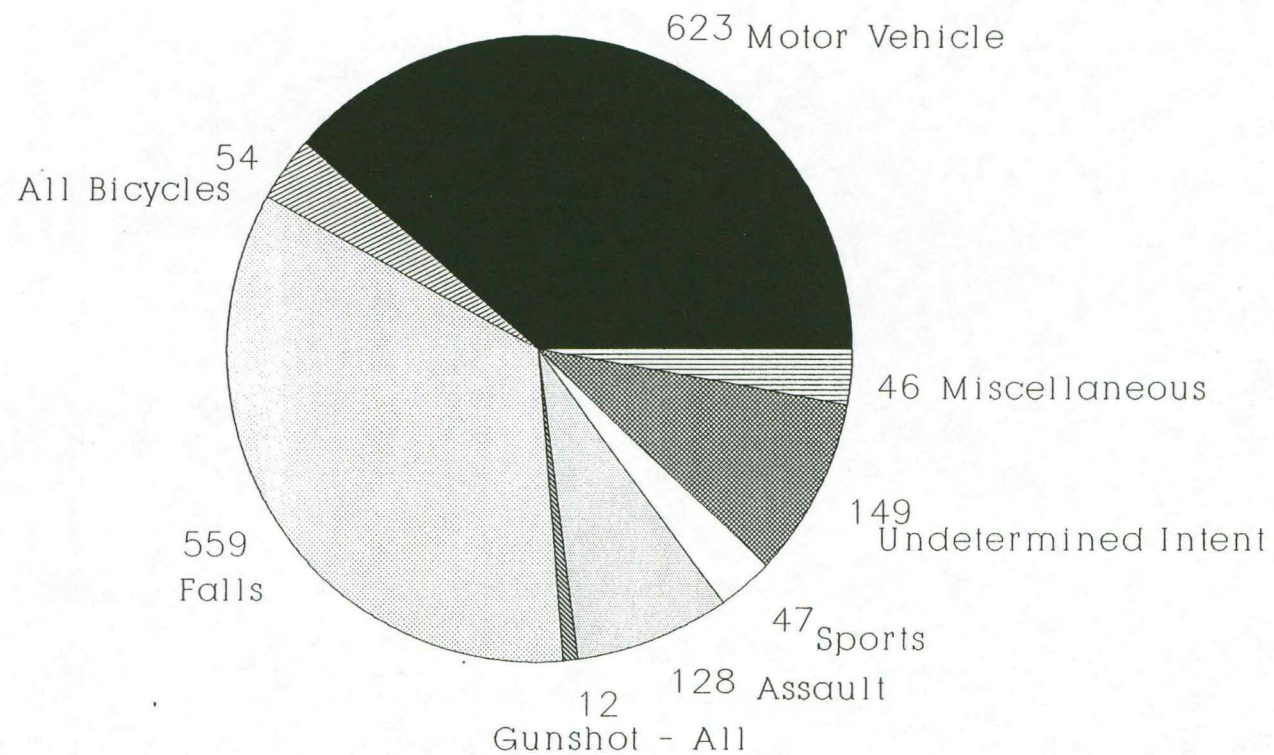
<u>Cause of Injury</u>	<u>&lt;1</u>	<u>1-4</u>	<u>5-14</u>	<u>15-24</u>	<u>25-44</u>	<u>45-64</u>	<u>65+</u>	<u>Total</u>
Motor Vehicle	5	17	36	221	184	55	33	551
Motorcycle	0	0	2	19	15	2	1	39
Pedestrian	1	5	14	5	4	1	3	33
All Bicycle	0	1	29	10	8	5	1	54
Falls	19	89	82	57	92	74	146	559
Gunshot	0	0	2	3	5	2	0	12
Assault	4	5	1	38	71	6	3	128
Sports	0	2	14	22	7	0	1	46
Undetermined Intent	1	6	7	10	14	6	3	47
Miscellaneous	<u>1</u>	<u>11</u>	<u>31</u>	<u>35</u>	<u>34</u>	<u>20</u>	<u>17</u>	<u>149</u>
Total	31	136	218	420	434	171	208	1,618

With Birth Date known  
4/22/93





Central Registry for Brain and Spinal Cord Injuries  
Hospitalized Traumatic Brain Injuries - 1991 - By Cause



N = 1,618 - Birth Year 1875 to Present; Sex Known





**APPENDIX J:**  
**MODEL SERVICE DELIVERY SYSTEM**

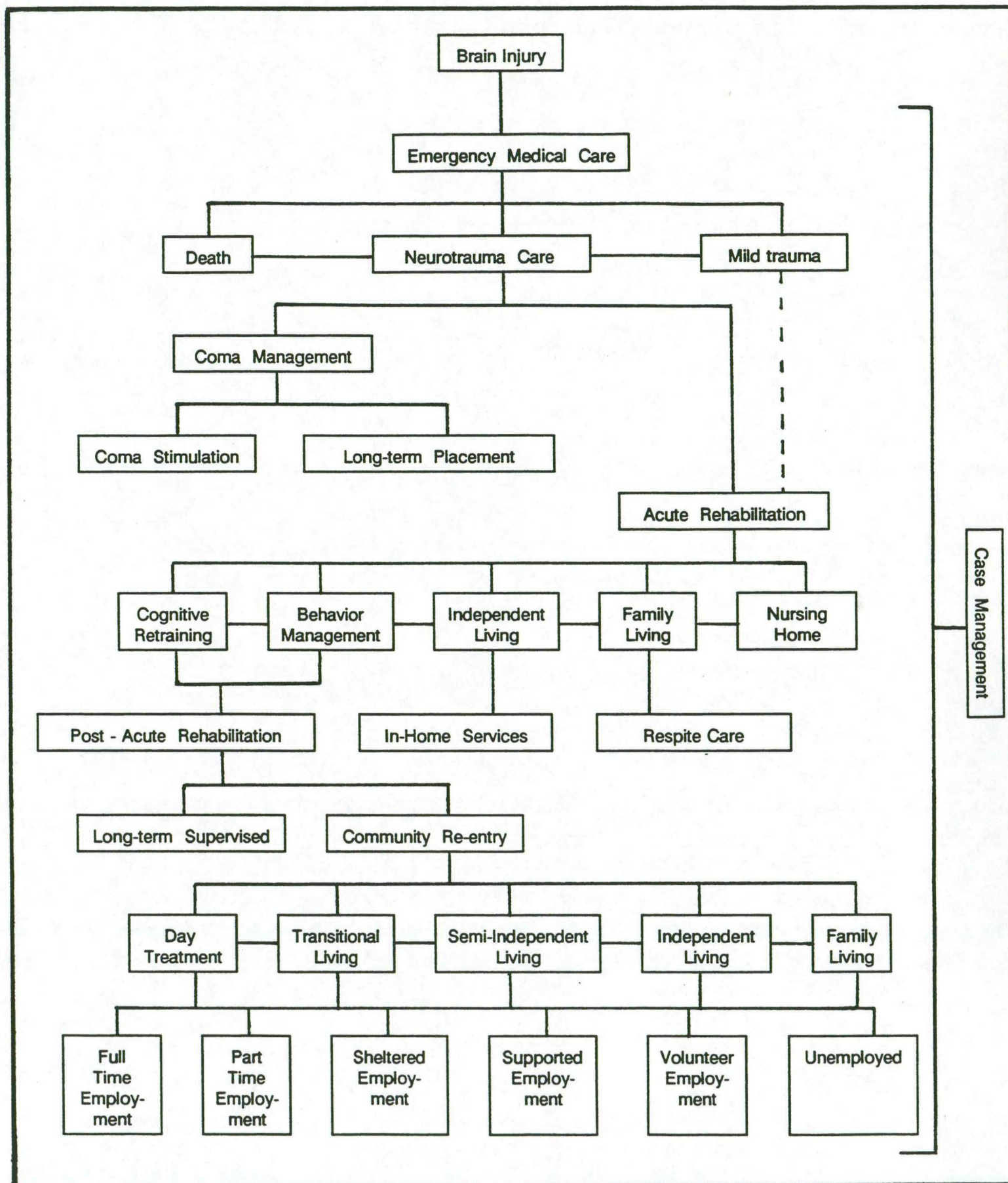




# 1992 MODEL SERVICE DELIVERY SYSTEM

*for Individuals with Brain Injury*

Prevention







## **ADDENDUM 1: RESOURCES**

Iowa's Educational Network for Brain Injury

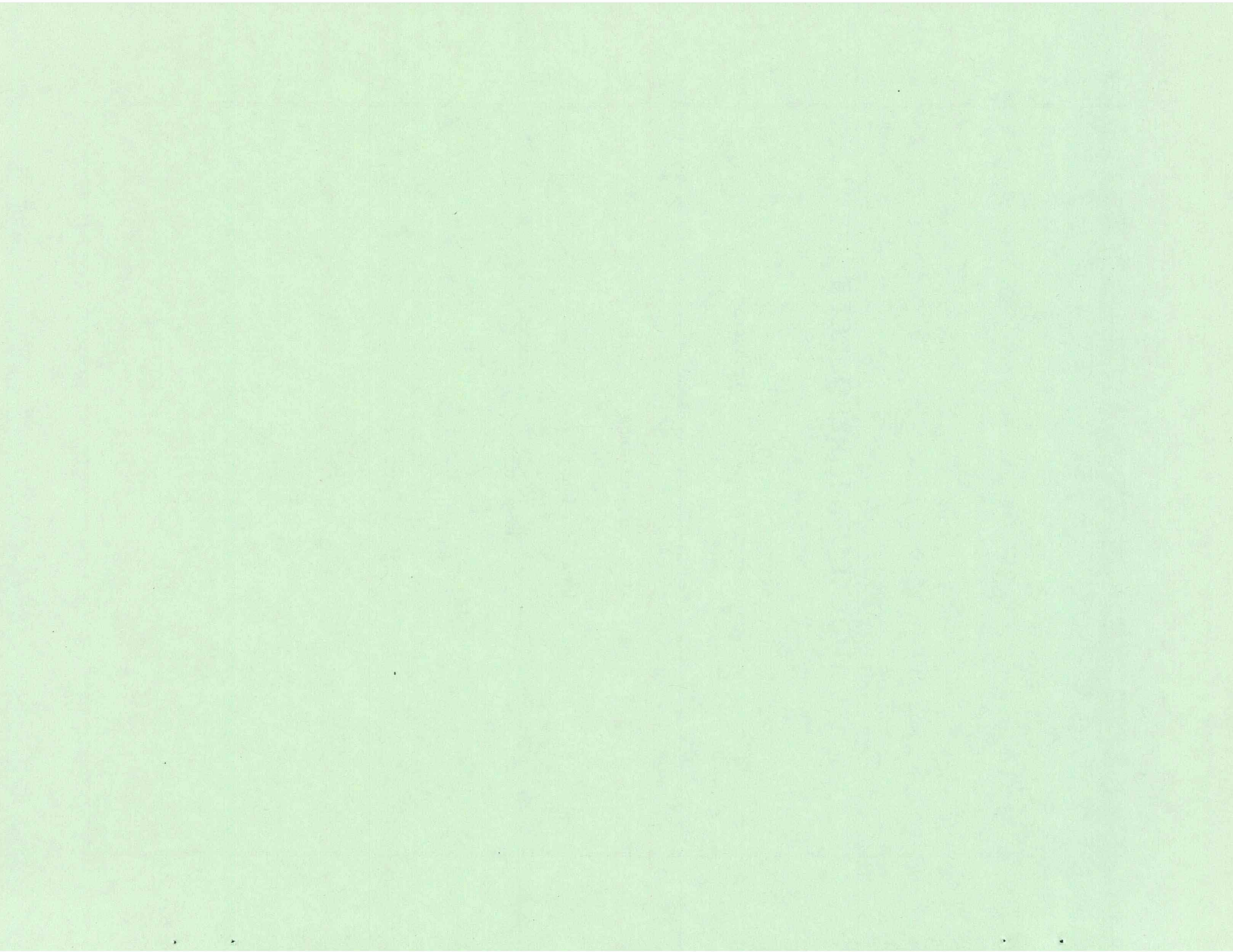
Pediatric Brain Injury Services

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 ReEntry model helps to ensure that the student's medical, educational, and social/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. Statistics obtained from the Iowa Central Registry for Brain and Spinal Cord Injuries indicate that during 1991, approximately 2,311 school-aged children sustained traumatic head injuries; 656 of these cases were serious enough to require hospitalization. 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 or 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 or 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 about 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 and the funding to pay for them.

## **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%); falls (23%); assaults (14%); falls from bicycles (6%); sports and recreation activities (6%); and all other injuries (8%).

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 to 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 less than five and more than 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: Eighty % 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 neuropsychological 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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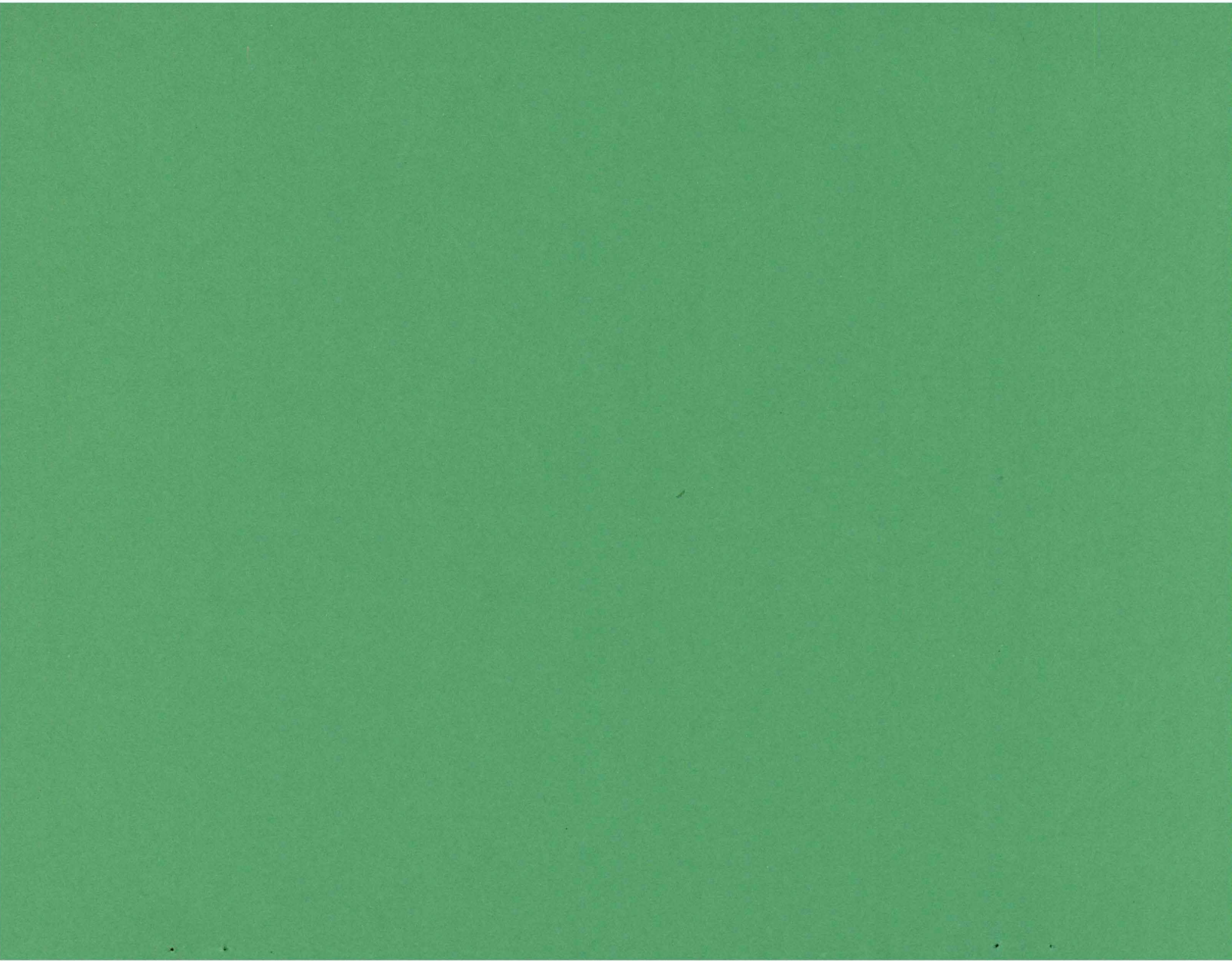
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