Iowa Plan for Brain Injury

October 2002 – September 2005

A product of the Iowa Department of Public Health
Iowa's Lead Agency for Brain Injury

In Cooperation with the Iowa Advisory Council on Brain Injuries, the Iowa Brain Injury State Plan Task Force, the Brain Injury Association of Iowa and its Iowa Brain Injury Resource Network, the University of Iowa Center for Disabilities and Development and College of Public Health, and the State of Iowa's Center for Health Statistics.

Iowa Department of Public Health

Promoting and protecting the health of Iowans

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Iowa Advisory Council on Brain Injuries

The Brain Injury Association of Iowa

University of Iowa Health Care
University of Iowa Hospitals and Clinics

University of Iowa
College of Public Health

TBI
TRAUMATIC BRAIN INJURY
STATE GRANT PROGRAM

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Table of contents

An index of acronyms and narrative identifiers are provided here for your reference:

- **ACBI** – Iowa's Advisory Council on Brain Injuries
- **AEA BIRT** – Area Education Agencies' Brain Injury Resource Teams
- **CHSC** – Child Health Specialty Clinics – Iowa's Title V Program for Children with Special Healthcare Needs
- **COMPASS** – Iowa's free, confidential guide to disability information and services, (800) 779-2001 or TTY at (877) 686-0032
- **CPC** – Central Point of Coordination – manages disability funds at the county level
- **IBIRN** – The Iowa Brain Injury Resource Network
- **IDPH** – The Iowa Department of Public Health
- **IFSN** – The Iowa Family Support Network of the IBIRN system
- **MH/DD Commission** – Iowa's Mental Health and Developmental Disabilities Commission
- **TBI** – Traumatic Brain Injury
- **TBI Council** – Iowa's Advisory Council on Brain Injuries
- **The Association** – The Brain Injury Association of Iowa

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Introduction

Cutting edge emergency services now allow many Iowans to survive a traumatic brain injury (TBI) that would have caused death just a decade ago. The discharge planners at medical centers struggle with dramatically shorter acute inpatient stays, increased caseloads, and over 2000 brain injury admissions each year. Historically, following discharge from the hospital, Iowans with brain injury and their families have been left with little understanding of brain injury, its long-term effects, or where to go for services and supports. One family described it like this, "Suddenly you're told on Monday that your loved one is being discharged on Friday, no one to turn to and nowhere to go…this is way too much to handle and it's very scary."

In 1998, the Iowa Department of Public Health (IDPH), the Center for Disabilities and Development at the University of Iowa, and the Brain Injury Association of Iowa, conducted a comprehensive statewide needs assessment of brain injury in Iowa. This assessment, linked with the oversight of Iowa's first State Plan Task Force, lead to the development of the first Iowa Plan for Brain Injury. The assessment data reflected that Iowa's brain injury service system was highly fragmented, that a vast majority of Iowans with brain injury suffer long-term problems, and that families had great difficulty linking to necessary services and supports. Iowa's first Brain Injury State Plan Task Force identified one of its top priorities as meeting the need for information and direction to resources. The IDPH utilized the state plan as the framework for an application to the federal TBI State Grant Program, which resulted in $600,000 for plan implementation.

Within the grant, six project goals were developed to address some of the major statewide needs: development of a pre-discharge planning model at five locations, development of a mentoring model for Iowa, identification of links to non-traditional resources, improvement of training and information resources related to TBI, development of an Iowa TBI web site, and evaluation of the above for system improvement. The overall purpose of the grant's projects was to begin organizing and linking the array of services and supports for children and adults with brain injury, in order to move Iowa toward a comprehensive, coordinated, and seamless system of care that respects the integrity of the individual and focuses on the needs of the family.

The IDPH has since been awarded two additional TBI grants and the Iowa Brain Injury Resource Network (IBIRN) system is the product of the past six years of the federal TBI grants. The IBIRN consists of 1) a pre-discharge planning system, which is now functional at 29 hospitals, service provider agencies, and advocacy organizations; 2) a peer-to-peer mentor network of 25 volunteer family members; and 3) a training program that offers technical assistance on brain injury, as well as a variety of educational and awareness trainings to community groups, service providers, and professionals. Staffs at each of the IBIRN locations provide families with specific information about brain injury and the services/supports that may be available to them. A number of new resources have been created, to include a TBI web site, training videos, and resource books for families and professionals. The IBIRN is managed as a program of the Brain Injury Association of Iowa and operates in partnership with the Iowa Department of Public Health. The IBIRN has improved Iowa's state and local capacity, enhancing access to services and supports available to its families experiencing brain injury.

1.
Brain Injuries in Iowa 1997 – 1999: Inpatient Admissions

(An executive summary prepared by the State of Iowa's Center for Health Statistics in September 2001)

The Iowa Code defines brain injury as "the occurrence of injury to the head not primarily related to a degenerative disease or aging process that is documented in a medical record with one or more of the following conditions attributed to the head injury: an observed or self-reported decreased level of consciousness; amnesia; a skull fracture; an objective neurological or neuropsychological abnormality; or, a diagnosed intra-cranial lesion."

This report includes data from 1997 – 1999 on inpatient admissions of persons with brain injuries. The data were obtained from the Statewide Inpatient Database, provided by hospitals to the Iowa Hospital Association and then to the Iowa Department of Public Health. Unfortunately, neither the Statewide Inpatient Database nor the Central Registry for Brain and Spinal Cord Injuries includes Iowans with brain injuries that are treated in out-of-state hospitals.

What are the consequences of a brain injury?

Each year as a result of a brain injury, more than 500 Iowans die, while hundreds more become permanently disabled. The long-term impact of these injuries can be devastating. The Centers for Disease Control and Prevention estimates that 50,000-55,000 Iowans have significant long-term disability from brain injury. As part of *Coming Into Focus*, Hoyt-Mack Research Associates found that of those surveyed:

- 81 percent reported one or more physical impairments;
- 92 percent reported memory difficulties;
- 64 percent reported problems in organizing daily activities;
- 75 percent reported difficulty making decisions;
- 76 percent reported emotional difficulties; and
- 84 percent reported learning difficulties.

How many were injured?

Nearly 6,500-brain injury hospital admissions occurred between 1997 and 1999, an average of 2,160 each year. Almost six of every 1,000 Iowa hospital admissions were for a brain injury. The 1998 data showed that about 10 percent were readmissions for the same injury. Consistent with national trends showing declining rates of brain injury hospitalization, the rate of brain injury admissions in Iowa dropped 13 percent between 1997 and 1999. Though no data is available, the decline may be due to changing admissions criteria and/or increased traffic safety initiatives, including those to increase the use of seat belts.

Using the Center for Disease Control and Prevention, National Center for Injury Prevention and Control's method to estimate the incidence of severe brain injury, it is calculated that about 2,400 – 2,650 brain injuries occurred in Iowa in each of the three years 1997 through 1999. This estimate includes both traumatic and non-traumatic brain injury resulting in death or in hospitalization.

Who was injured?

Both nationally and in Iowa, males are at significantly greater risk than females for brain injury. The rate of hospital admission was more than 70 percent higher for males than for females. In terms of age, males 15-24 years of age had brain injury admission rates 2.5 times that of females of the same age. Males in this age group accounted for 12.7 percent of all brain injury hospitalizations though they comprise only 7.4 percent of the state's population.

Inpatient admissions for brain injury increase dramatically after age 65. In 1999, the elderly accounted for 15 percent of the Iowa population but accounted for 34 percent of all brain injury admissions. Admission rates for those 85 and older are five times greater for males and nine times greater for females than those who were age 55 to 64.

Nearly a quarter of people admitted for brain injury have no race identified; however, for those that do, 95.7 percent were of Caucasian; 2.4 percent were of African-American; and, 1.9 percent were of Native American, Asian or Pacific Islander, descent. The rate of brain injury admissions in 1999 was highest in African-American males and paradoxically, lowest in African-American females.

What caused the injuries?

Motor vehicle crashes and falls were the two leading causes of brain injury hospitalizations in 1999, accounting for more than 62 percent of admissions. Of those injured in transportation-related crashes:

- 72 percent were in motor vehicles;
- 14 percent were on motorcycles;
- Six percent were pedestrians; and
- Three percent were bicyclists.

Males accounted for 63 percent of all motor vehicle-related brain injury admissions in 1999 and those ages 15 – 54 accounted for 69 percent of admissions for motorcycle-related brain injuries. Young persons ages 15 through 24 had the highest rate of motor vehicle-related brain injury admissions of all age groups. They account for 30 percent of brain injury hospitalizations, but only 14.5 percent of the Iowa population.

In 1999, falls were the second most frequent cause (31 percent), accounting for nearly one-third of all brain injury admissions. Sixty-two percent of all brain injury fall-related admissions occurred among those 65 and older. Assaults were the third most frequent cause, accounting for about four percent of the hospitalizations in each of the three years.

How serious were the injuries?

Of the 6,475 brain injury inpatient admissions from 1997 through 1999, 60 percent of the patients were sent home, 24 percent went to a nursing, custodial or rehabilitation facility, nine percent died prior to discharge, and six percent were transferred to another hospital. The length of stay for those whose cause of injury was not provided was the longest for all admitted. Of those whose reason for admission was known, those who sustained their injuries from motor vehicles crashes had both the longest length of stay and the highest hospital costs.

What and who was charged for the inpatient care?

The average inpatient charges documented in the Statewide Inpatient Database, exclusive of professional fees, emergency department and after care, were highest for those injured (drivers and passengers) as a result of motor vehicle crashes and this care averaged $30,787 in hospital charges. Treatment for those with fall-related brain injuries cost an average $23,419.

In 1999, the overall average inpatient charge for a brain injury was $22,490 and the total cost for inpatient admissions exceeded $45.6 million. Private insurers paid the largest share of acute care costs (47.8% on average), followed by Medicare, “self-pay” and Medicaid. Almost eight percent had no medical insurance coverage and another one to three percent relied on county or state funds to pay for their care. During the three years studied, the average inpatient charges per admission increased 21percent.

How can brain injuries be prevented?

Prevention efforts to reduce the number, severity, and sequelae of brain injuries are key to reducing the significant psychosocial and economic burdens of brain injury on those injured, their families and their communities. *Healthy Iowans 2010*, a planning document outlining public health intervention needs over the next ten years, contains several chapters that address prevention and health services interventions to reduce the impact of unintentional and intentional injuries. Objectives contained in those chapters that directly or indirectly address brain injury include those that seek to:

- assure that all are served by an effective emergency medical services system;
- reduce falls through better surveillance and progressive resistance training for the elderly so that their functional fitness is improved;
- reduce firearm-related injuries through education in the schools and in the community about proper storage of ammunition and firearms;
- confiscate and store firearms possessed by persons convicted of violent crimes and require all handguns sold in the state to possess mechanisms to prevent anyone but the owner from using them;
- establish better surveillance systems to record firearm injuries, and other violent acts, including victimization of adults/children and school/workplace-based violence;
- screen all substance abuse treatment program clients for domestic abuse and all domestic abusers for substance abuse;

- reduce child abuse through improved respite care, mentoring and other supportive programs;
- increase funding for investigation of elder abuse;
- establish a state level task force on school and workplace violence to develop a prevention action plan;
- reduce playground-related injuries through better surveillance, use of national playground safety standards and education of persons responsible for playgrounds;
- decrease motor-vehicle-related fatalities through driver education, increased enforcement of laws regarding drunken driving, child safety restraints and seat belt use;
- reduce head injuries by increasing the use of helmets by bicyclists and motorcyclists, and through motor vehicle prevention education in the primary and secondary schools; and
- reduce water-related injuries through increased testing by officers of operators for drug or alcohol consumption, increased supervision of young operators and better drowning reporting.

2.
The Iowa Brain Injury Resource Network and Follow-up Survey

The Iowa Brain Injury Resource Network (IBIRN) is the product of the past six years of the IDPH's *Meeting the Needs of Iowans with Traumatic Brain Injury* federal grant projects. The *Iowa Brain Injury Follow-up Survey* is the data collection tool used to measure the impact of the IBIRN. Prior to highlighting the feedback from Iowans that have benefited from these supports it is important to provide a short history of the IBIRN. The IBIRN consists of 1) a pre-discharge planning system, which is now functional at 29 hospitals, service provider agencies, and advocacy organizations; 2) a peer-to-peer mentor network of 25 volunteer family members; and 3) a training program that offers technical assistance on brain injury, as well as a variety of educational and awareness trainings to community groups, service providers, and professionals. Staffs at each of the IBIRN locations provide families with specific information about brain injury and the services/supports that may be available to them.

The overall purpose of the grant's projects was to begin organizing and linking the array of services and supports for children and adults with brain injury, to move Iowa toward a comprehensive, coordinated, and seamless system of care that respects the integrity of the individual and focuses on the needs of the family. The IBIRN has utilized its projects to empower families, recognizing that they are the primary support system for each individual experiencing a brain injury.

How did the projects develop and who implemented them?

The pre-discharge planning model and mentoring model were developed and implemented through two sub-contracts, one with the University of Iowa, Center for Disabilities and Development and the other with the Brain Injury Association of Iowa. In year one, seven statewide focus groups, consisting of over 120 people with brain injuries and family members, identified the principles to use in pre-discharge planning and mentoring. They identified the need for identification of links to non-traditional resources, improvement of training and information resources related to brain injury, and the development of an Iowa TBI web site.

In 1999, project staff created a standardized discharge process for implementation at five pilot hospitals and rehabilitation centers. A key piece to this process was the creation of the IBIRN tote bag of information. The tote bag contains information on brain injury and links to additional resources, services, and supports available across the state. Discharge planners and hospital staffs provide the tote bag to families for use during the rehabilitation process and beyond.

The Brain Injury Association of Iowa was responsible for the creation of the Iowa Family Support Network (IFSN) mentoring model. The support network consists of 25 peer mentor volunteers who have personally experienced the brain injury of a family member. These trained volunteers are contacted by the IBIRN staffs as early as possible in the acute phase of recovery and respond within 24 hours, if the new family is accepting of this type of support. The volunteer visits with the family in crisis, providing mentoring and emotional support. The two families decide the length and frequency of continued contact in accordance with their own comfort levels.

A variety of resources have been created to begin meeting the needs identified by families in *Coming Into Focus* and a few are highlighted here. A brain injury web site (www.biaia.org) became functional in July of 1999 and has had over 4,300 visits. An Internet resource, “Brain Injury Resources for the WWW,” was created for use in the tote bag and can also be distributed using e-mail. This resource contains over 115 websites that address many of the information needs identified. Two videos, “Pieces of the Puzzle: An Introduction to Brain Injury” and “The Outside to the Inside: Including Students with Brain Injury” were created for training purposes and/or for use in the tote bag. “Pieces” won “Best Corporate Training Video under $15,000” at the *9th Annual Iowa Motion Picture Awards* on April 1, 2000.

Today, the Brain Injury Association of Iowa is the sole subcontractor for the operation of the Iowa Brain Injury Resource Network, which includes both the discharge planner and peer mentor programs. The IBIRN is in its third year of existence and the consolidation of programs took place in July of 2001 to streamline program activities and to reduce costs for long-term financial sustainability. The IBIRN now consists of 29 medical centers/hospitals, rehabilitation centers, and program locations, which provide the necessary information to families experiencing brain injury. The IBIRN program director and the IDPH Brain Injury Program manager provide technical assistance, training, and support to each of the IBIRN locations.

What have family members reported?

The *Iowa Brain Injury Follow-up Survey* was created as an evaluation tool to measure the impact of the IBIRN. A total of 763 surveys were mailed to persons with brain injury, both before and after project implementation. The University of Iowa, College of Public Health completed the initial data collection and evaluation, and the State of Iowa's Center for Health Statistics provided the final analysis. A total of 237 surveys were returned producing a 37 percent response rate. Responses were received from people with brain injury, family members, friends, healthcare professionals, and others representing the person with the injury. Given the IBIRN focus of empowering family members, the following summarizes the quality of life measures that they reported. Those receiving IBIRN support will be identified as the IBIRN group and those not receiving information will be identified as the control group.

When family members were questioned about whether their home was a stressful place to live, 57 percent of the IBIRN group stated that they strongly disagreed. Only 35 percent of the control group stated the same. Family members reporting a lot of strain on the members of their family also varied greatly when the receiving of information was factored in. In the IBIRN group, 59 percent disagreed or strongly disagreed that there was a lot of strain on the members of their family, compared to only 36 percent of the control group.

The survey also questioned about getting the social and emotional support they need. Of those in the IBIRN group, 73 percent reported they always, usually, or sometimes get the social and emotional support they need. None of the IBIRN group respondents reported they never get the support they need, compared to 22 percent of the control group. When questioned about how many of the past 30 days they felt sad, blue, or depressed, 50 percent of the IBIRN group reported zero days, compared to 14 percent of the control group. When questioned on how many of the past 30 days they felt very healthy and full of energy, 46 percent of the IBRIN group reported 25 or more days a month, compared to only 19 percent of the control group.

In this limited preliminary study, data reflects the unmistakable impact of the IBIRN system on the quality of life indicators reported by family members and the reported ability of the members to cope with the experience of brain injury. Since the completion of the study, the IDPH has implemented a consumer feedback form, which is now contained within the IBIRN tote bag of brain injury information. At this time, responses are only received from those families that voluntarily mail the feedback form, i.e. there is no formal request for feedback.

The feedback reflects a 96 percent satisfaction rate when questioned if the tote bag contained information that was useful and beneficial to their understanding of brain injury. Secondly, an 88 percent satisfaction rate was reported when questioned if the tote bag contained information that assisted them in accessing appropriate and acceptable supports and services. Lastly, respondents reported an 80 percent satisfaction rate when questioned if they felt the Iowa Family Support Network contact was beneficial. This outcome data is central to the planning and executing of future research studies. Families must have information about brain injury and access to statewide resources, services, and supports.

3.
The 2002 Iowa Plan for Brain Injury
October 2002 – September 2005

What can be done to improve services and supports for Iowans with brain injury and their families?

In 1998, the State Plan Task Force of the Advisory Council on Brain Injuries (TBI Council) developed the first Iowa Plan for Brain Injury. This plan was Iowa's first official answer to the above question. The plan was developed from Iowa's first statewide needs assessment of people with brain injury, their families, and the service providers that serve them. The final report, *Coming Into Focus: A Needs Assessment and State Plan for Iowans with Brain Injury* has been instrumental in leveraging funds to enhance the capacity of Iowa's service system to support and serve Iowans experiencing brain injury and their families.

In November of 2001, the Iowa Department of Public Health (IDPH) and the TBI Council began the process of updating the 1998 plan. It was decided that the constituency of the State Plan Task Force again needed to be broadened beyond that of the TBI Council to ensure that a comprehensive statewide plan would be created. In February 2002, invitation letters were sent to the identified constituents; and the membership of the 2002 Iowa Brain Injury State Plan Task Force is identified on page ii of this document.

In February 2002, the IDPH asked for public comment from over 17,500 people with brain injuries and their families, professionals and advocates in brain injury, county officials, State of Iowa employees, the TBI Council, and current TBI grant participants. The request asked individuals to "tell us how the system of services and supports have changed for persons with brain injury since the 1998 plan's implementation and/or make any other comments you feel will be important for the state plan revision." The input was used to prepare the 2002 Iowa Brain Injury State Plan Task Force for its initial meeting.

The Iowa Brain Injury State Plan Task Force was convened in March of 2002. At its initial meeting Janet Zwick, IDPH deputy director, stressed the importance of developing a long-term plan to initiate change. She stressed the importance of working collaboratively with other departments and divisions. She expressed the need to build on existing plans, such as Healthy Iowans 2010, and that the plan needed to focus on accountability, performance measures, and measurable goals and objectives. She urged the task force to move forward with a strategic planning process that will assist other boards, groups, commissions, and agencies in meeting their established goals. The task force's final product is outlined in the updated Iowa Plan For Brain Injury.

Priority Areas of Focus: The 2002 Iowa Brain Injury State Plan Task Force believes that a major effort is needed to focus on aspects of preventing brain injury. While prevention is paramount to our future, so are many issues and needs that must be addressed in order to assure that individuals and their families who are or will live with brain injuries will receive the necessary services and supports to live their lives to the fullest. The 2002 Iowa Brain Injury State Plan Task Force has identified four priority areas of focus for the next three years and prevention concepts are woven throughout the plan.

1) **Expand the IBIRN System:** While significant gains have been made in establishing the Iowa Brain Injury Resource Network (IBIRN) system (see section two), there are many acute, post-acute, and community based locations across the state, which are not knowledgeable of the IBIRN and thus, the families they serve do not benefit from the IBIRN. These service providers are not aware of the resources, support, technical assistance, and training available to them and the families they serve.

2) **Promote a Legislative and Policy Agenda, While Increasing Legislative Strength:** There is a need to continue focus on changing policy and legislation, and expanding outreach to "grass root constituents." The Advisory Council on Brain Injuries and the Brain Injury Association of Iowa have been the lead brain injury advocacy groups over the past thirteen years. It is essential that they continue to broaden their outreach to cross disability constituents and build on already established disability service systems (i.e., case management).

3) **Enhance Data Collection:** The Iowa Brain Injury Follow-up Survey and the tote bag feedback form, described in section two of this report, has produced preliminary data that supports the need for continued research to identify the impact of the IBIRN system. The brain injury data collected through Iowa's registries needs to be evaluated on a regular basis to identify changes in trends and service needs for both prevention strategies and service capacity building strategies. The enhancement of outcome and incidence data collection will assist with legislative and funding priorities, and assist in the identification of needs for future system redesign efforts.

4) **Increase Funding:** Given the current, almost constantly changing budget environment, it is essential that varied funding sources be identified for each of the above priorities. Possible funding sources must be identified at the federal, state, local, and private levels. A long-term funding source for the IBIRN must be identified.

THE PLAN

AREA 1

Expand the IBIRN System

Rationale: There are many acute, post-acute, and community based service/support providers that are not knowledgeable of the IBIRN and thus, the families they serve do not benefit from the IBIRN. Additionally, these service providers are not aware of the resources, support, technical assistance, and training available to them and the families they serve.

Annually Year 1 – Year 3

- Promote recognition of brain injury and the IBIRN system
  - The IDPH and the Association will conduct a minimum of eight brain injury trainings
  - The Association will run ads for the IBIRN system in its quarterly newsletter
  - The Association will work with the governor's office to designate October as Brain Injury Awareness Month
  - The IDPH and the TBI Council will collaborate with the Association on its Central Area Support Groups Brain Injury Awareness Walk
  - The Association will coordinate with the Area Education Agencies' Brain Injury Resource Teams (AEA BIRT) and Child Health Specialty Clinics (CHSC) to promote service and prevention efforts for children in the school and communities

Year 1

- Promote recognition of brain injury and the IBIRN system
  - The IDPH and the Association will develop a brochure for the IBIRN system and disseminate as necessary

- The Association will expand the IBIRN system by 100%, giving specific focus to children and culturally distinct rural populations; and expand its family support network by 25%
  - The TBI Council, with assistance from IDPH and Department of Education, will develop a plan for outreach in rural areas with local level III hospitals and with the AEA BIRTs by 9/30/03

- Develop linkages with the counties' Central Points of Coordination (CPC)
  - The IDPH will provide CPCs with resource materials and professional contacts
  - The IDPH and the Association will submit proposals to present at the biannual trainings for county employees, "Winter and Spring Schools"

- Improve access to information about brain injury service providers and assistive technology
  - Develop a brain injury fact sheet for the COMPASS website and enhance its brain injury service descriptions

- Develop a booklet on assistive technology for use in the tote bags

- The Association will hold an educational conference focused on meeting the service training needs of Iowa's provider system and hold a best practices forum for the IBIRN system participants

Year 2

- The Association will expand the IBIRN system by 50%, giving specific focus to children and culturally distinct rural populations; and expand its family support network by 25%
  - The Association will promote coordination between AEA BIRT and CHSC's regional centers with an IBIRN Best Practices Forum by 4/15/03
  - The Association will implement an outreach plan for rural level III hospitals and Area Education Agencies' Brain Injury Resource Teams by 9/30/04
  - The Association will develop a plan for outreach to child care centers and juvenile detention shelters by 3/31/04
  - The Iowa Department of Human Services and the Association will develop a plan for outreach to brain injury waiver providers by 3/31/04
  - The Association will develop a web-based resource to meet multi-cultural needs for information by 3/31/04

- Intensify and tailor linkages with the counties' Central Points of Coordination (CPC)
  - The Association will make outreach calls to all CPC's to identify their needs for support, assistance and training, and evaluate if this will become an annual practice by 12/31/03
  - The Association and IDPH will provide yearly "tech" support based on needs by 10/31/04

- Coordinate with already established prevention efforts such as Safe Kids Coalition, Farm Bureau, Governor's Traffic Safety Bureau, Iowa Center for Agricultural Safety and Health, and Emergency Medical Services for Children
  - The Association, TBI Council and IDPH will establish a plan to coordinate with existing prevention efforts by 12/31/03
  - The Association, the TBI Council and the IDPH will implement the coordination plan by dates established in the plan

- The TBI Council will create a task force to influence attitudes and change perspectives that result in a shift from maintenance to a greater rehabilitation focus for Iowans with brain injury by 10/31/04

Year 3

- The Association will expand the IBIRN system by 33%, giving specific focus to children and culturally distinct rural populations; and, expand its IFSN by 25%
  - Implement outreach plan to childcare centers and juvenile detention shelters

- The Association will, in association with other identified partners, coordinate planning with project coordinator for Healthy Childcare Iowa and juvenile justice system by 10/01/05
- The Association and IDPH will provide brain injury training for regional child health consultants through the Healthy Child Care Iowa initiative by 9/30/05
- The Association and IDPH will collaborate with juvenile justice system to obtain funding for training juvenile justice shelter representatives by 9/30/05

- The Association will implement outreach plan to brain injury waiver service providers by 10/1/04

AREA 2

Promote a Legislative and Policy Agenda, While Increasing Legislative Strength

Rationale: The disability service system continues to be highly fragmented and/or nonexistent for meeting the needs of Iowans with brain injury and their families. There are a number of system redesign projects taking place in Iowa; it is very important for Iowa's brain injury constituents to participate in the system redesign efforts.

Annually Year 1 – Year 3

- The TBI Council and the Association will, in collaboration, develop and promote a legislative agenda, which will include a prevention component(s).
  - The TBI Council will develop a legislative agenda at its annual council meeting in collaboration with the Association
  - The Association will hold a legislative "day on the hill" to promote brain injury awareness and the adopted legislative agenda
  - The Association will actively work to shape and respond to legislation and public policy impacting Iowans living with brain injuries, their families and providers of service
  - The Association will monitor brain injury and disability related legislative information and notify Iowa's brain injury constituents when necessary

- Iowa's brain injury constituency will become involved with and/or maintain involvement in current and future redesign efforts (such as the MH/DD Commission's System Redesign, Home and Community Based Waiver Re-design, and Olmstead related activities)

- The Association and the TBI Council will work to increase the legislative strength of the brain injury constituency in Iowa
  - Continual collaboration with the state's chief election official on annual advocacy training and voter registration issues

- Incorporate advocacy training, review of TBI Council legislative priorities and prevention activities in to the annual Provider's Conference in the spring and the Family Conference in the fall
  - Organize constituent invitations to legislators for both conferences

Year 1

- Iowa's brain injury constituency will become involved with and/or maintain involvement in current and future redesign efforts
  - Representatives from the TBI Council, the Association, and other brain injury constituencies will apply for workgroup appointment to the MH/DD Commission's redesign effort
  - Representatives from the IDPH and the TBI Council will maintain participation in Iowa's Real Choices System Change Grant in their role as members of the Olmstead Real Choices Consumer Taskforce

Year 2

- The Association and the TBI Council will work to increase the legislative strength of the brain injury constituency in Iowa
  - The Association will develop an e-mail distribution list for disseminating brain injury and disability related legislative information by 12/03
  - Add links to the Association's web site: MH/DD System Redesign**,** Governor's Developmental Disabilities Council, Olmstead Real Choices Consumer Task Force, Department of Education, and IDAction by 12/31/03
  - Add to the Association's web site a legislative page and the legislative agenda by 10/03
  - The Association will partner with the Governor's DD Council to add to the Association web site a page for updating legislative actions on a bi-weekly basis while the legislature is in session by 1/04

Year 3

- The TBI Council and the Association will, in collaboration, develop and promote a legislative agenda to include prevention efforts
  - The Association and IDPH will add to the Association's web site information about prevention by 12/31/04
  - The Association and IDPH will develop PSA's supporting the TBI Council and the Association sanctioned legislative proposals i.e. child restraint seats, bike helmets by 12/31/04

AREA 3

Enhance Data Collection

Rationale: Enhancing outcome and incidence data collection will assist with legislative and funding priorities, and assist in the identification of needs for future system redesign efforts.

Annually Year 1 – Year 3

- The IDPH will produce annual reports in April of each year, on "Brain Injury in Iowa" based on the creation of a TBI data system (Years 2 – 3)

- The IDPH will produce annual reports on the impact of the IBIRN system from survey outcome data collected

Year 1

- The Advisory Council on Brain Injuries and the IDPH will revise the Iowa Brain Injury Follow-up Survey to focus on family member input. The new survey will be utilized to determine if the positive impact of the IBIRN system identified in the previous survey is valid when a larger sampling format is utilized

- *IBIRN Feedback Survey and Long-term Follow-up Agreement* will be sent to all individuals admitted to Iowa hospitals between October 1, 2001, and September 30, 2002

- IDPH Center for Health Statistics staff will create a database program to enter and evaluate survey data from the *IBIRN Feedback Survey*

- An executive summary will be written to summarize the history of the IBIRN. The executive summary will contain the compiled data from the *IBIRN Feedback Surveys* collected by March 1, 2003.

Year 2

- Create a data Collection System to allow the creation of a TBI information system which may include: Trauma Registry Report, Vital Records, Hospital Discharge Data and IBIRN, Medicaid, DOT Crash Data, Behavioral Risk Factor Surveillance System Data
  - IDPH will solicit TBI Council input re: format for the TBI in Iowa information system report and establish a draft format by 12/1/03
  - IDPH will identify information gaps and how to fill them by 2/15/03

- An executive summary will be written to summarize the compiled data from the *IBIRN Feedback Surveys* collected from recipients of the IBIRN tote bags (data will reflect surveys returned between March 1, 2003 and March 1, 2004), by 6/01/04

- The TBI Council will provide funding for the IDPH Center for Health Statistics to compile a report, “Brain Injuries in Iowa 2000 – 2002,” reflecting the structure of the “ Iowa Plan for Brain Injury 2002-2005.” This report will be a follow-up to the 1997 to 1999 report, and be produced by IDPH by 4/04

Year 3

- The TBI Council will fund an annual report, “Brain Injury in Iowa 2003,” that follows the Iowa Plan for Brain Injury 2002-2005, utilizing data from the newly created TBI information system produced by IDPH by 4/05

- An executive summary will be written to summarize the compiled data from the *IBIRN Feedback Surveys* collected from recipients of the IBIRN tote bag (data will reflect surveys returned between March 1, 2004 and March 1, 2005) by 6/01/05

AREA 4

Increase Funding

Rationale: Given the current, almost constantly changing budget environment, it is essential that varied funding sources be identified for each of the above priorities. A long-term funding source for the IBIRN must be identified.

Annually Year 1 – Year 3

- The IDPH will continue to apply for federal grants to expand and improve the IBIRN system and to fund additional initiatives

- Continually monitor and find opportunities to expand funding under the Medicaid Home and Community Based Services Brain Injury Waiver

- Explore and identify potential private/corporate funding sources for prevention activities
  - Identify appropriate links between corporate missions and appropriate data
  - Identify community service funds available through corporations
  - Ensure the use of PSA's, etc. in the state of Iowa

- Remain actively involved in the development and implementation of MH/DD System Re-design
  - Regularly attend scheduled redesign work groups (Access, Fiscal, Support Design, and Roles and Responsibilities)
  - The Association and the TBI Council will regularly communicate with the brain injury representative on the MH/DD Commission regarding brain injury in Iowa and related long-term service needs for their use in updating the entire MH/DD Commission

Year 1

- Utilize the IDPH annual reports on the impact of the IBIRN system for necessary systems and policy change

- Actively work with the MH/DD Commission Fiscal Work Group to assure the addition of brain injury funding within the framework of the new system re-design

Year 2

- Utilize the IDPH annual reports on the impact of the Brain Injuries in Iowa report for necessary systems and policy change

- The TBI Council and IDPH will analyze survey data and recommendations will be made to initiate necessary systems and policy changes to Iowa's MH/DD Commission and, state and county government officials by 9/30/04

- The TBI Council, the Association and IDPH will continue to work with the MH/DD Commission and the Iowa General Assembly to insure the availability of funding for Iowans with brain injury in the new system re-design.
  - The Association will provide data to the brain injury representative of the MH/DD Commission that supports the need for flexible funding from all levels - federal, state, and county
  - IDPH will distribute the completed "Brain Injuries in Iowa" report to the entire MH/DD Commission by 5/04

- The TBI Council will actively pursue the establishment of an Iowa Brain Injury Trust Fund to support IBIRN by 12/31/03

Year 3

- Utilize the IDPH annual "Brain Injuries in Iowa" report for necessary systems and policy change.
  - Association and IDPH will have made funding presentations and requests to IBIRN program locations and will have identified potential sources of sustainability funds for the project year beginning 10/1/05.
  - The TBI Council and IDPH will assure survey data will be collected through 3/1/05 and analyzed, and recommendations will be made to initiate necessary systems and policy changes to Iowa's Mental Health and Developmental Disabilities Commission and, state and county government officials by 9/05

- Explore and identify potential private/corporate funding sources for prevention activities
  - The Association, in cooperation with the TBI Council, will identify 3-5 potential private/corporate funding sources for Iowa prevention activities by 9/21/05
  - The Association will make at least one contact to produce and or promote a televised PSA for brain injury prevention by a date appropriate to the PSA content

A representative from one of the IBIRN system locations ties the success of the “Coming Into Focus…” and the previous state plan together like this:

> As professionals who work daily with Iowans with brain injury and their families, we can testify to the impact that the Iowa Brain Injury Resource Network has had on them. The support that the IBIRN provides is the "Ever-Ready Bunny" that these individuals can count on. This valuable service can be implemented at any time during their recovery, beginning with their acute stay, and following them long after they leave our doors. We provide the brain injury tote bag to all of the brain injury patients’ families we come in contact with. The beauty of this information is that the provider does not have to be an expert on brain injury to supply this to the patient and families. The material is very comprehensive, current and written in a manner understandable by a wide population. Having the IBIRN staff representatives available is invaluable to professionals such as us who are at the bedside working with these patients and their families. They provide us with the current information, educational opportunities, materials, and support necessary to provide quality care to our patients.

Financial contributors of matching funds for the past six years of TBI State Grant Program funds from the Health Resources and Services Administration, Maternal and Child Health Bureau:

- The Iowa Department of Public Health and the Department of Education
- The Brain Injury Association of Iowa
- The University of Iowa
- The Pilot Club of Iowa City
- Pilot Club International
- The Mid-Iowa Health Foundation
- The Iowa Association of Rehabilitation Nurses