



Coming into Focus

A Needs Assessment and State Plan
for Iowans with Brain Injury

A project of the Iowa Department of Public Health

With the Iowa Advisory Council on Head Injuries
and The Iowa University Affiliated Program

November 1998

Coming into Focus

A Needs Assessment and State Plan
for Iowans with Brain Injury

Prepared For:

The Iowa Advisory Council on Head Injuries
and Its State Plan Task Force

Prepared By:

The Iowa Department of Public Health,
Bureau of Disability Prevention through
The Iowa University Affiliated Program
and Hoyt-Mack Research Associates

Part of the funding for this project
was provided by a Maternal and Child Health Grant
(Traumatic Brain Injury (TBI) Demonstration Grants Program, CFDA #93.234A)



ADVISORY COUNCIL ON HEAD INJURIES Iowa Department of Public Health

Ed Boll Village Northwest Unlimited	Angela Hance Creston	Geoffrey Lauer Brain Injury Association Of America	Marvin Tooman, EdD On With Life
Margaret J. Curry Danville	Roger Hoffmann University Hospital School	John A. May, MD Des Moines	Theodore Wells Iowa City
Laurie Dyer Des Moines	Joni Henderson Independence	Beverly J. McClung Mason City	Robert Vander Plaats Opportunities Unlimited
Emily Emonin Fairfield	Delbert L. Jensen St. Ansgar	Esthyr Ropa Iowa Division of Vocational Rehabilitation	Paul DeBoer Iowa Department of Public Health
Dave Greimann Work Consultants	Karen A. Johnson Davenport		

EX-OFFICIO MEMBERS ADVISORY COUNCIL ON HEAD INJURIES

Christopher G. Atchison, Director
(Roger Chapman, Representative)
Department of Public Health

Terry Dillinger, Director
(Scott Falb, Representative)
Office of Driver Services
Department of Transportation

Ted Stillwell, Acting Director
(Sue Pearson, Representative)
Department of Education

Almo Hawkins, Director
(John Ten Pas, Representative)
Department of Human Rights

Margaret Knudsen, Administrator
(Ruth Burrows, Representative)
Division of Vocational Rehabilitation

Charles Palmer, Director
(Janet Shoeman, Representative)
Department of Human Services

R. Creig Slayton, Director
(Bonnie Lindquist, Representative)
(Jane O'Brien, Representative)
Department for the Blind

Theresa Vaughan, Commissioner
(Angela Burke-Boston, Representative)
Iowa Insurance Division

PLANNING PROJECT PERSONNEL AND CONSULTANTS

Department of Public Health

Janet Zwick
Project Director

Roger Chapman
Project Manager

Paul DeBoer
Project Coordinator

Mario Schootman
Epidemiologist

Iowa's University Affiliated Program

Roger Hoffmann
Project Director

Barbara Smith
Needs Assessment Coordinator/Writer

Loretta Popp
Design Artist

Jude West
Planning Facilitator

Mary McIntosh
Administrative Support

Hoyt Mack Research Associates
Research Consultants

STATE PLAN TASK FORCE MEMBERS

Marilyn Adams
Farm Safety 4 Just Kids
Earlham, IA

Karen Armstrong
Victorian Acres Rehabilitation
Altoona

Ed Boll
Village Northwest Unlimited
Sheldon

Angela Burke-Boston
Attorney-at-Law
Insurance Division
Des Moines

Ruth Burrows
Department of Education
Division of Vocational Rehabilitation
Des Moines

Pat Crawford
Exceptional Persons, Inc.
Waterloo

Margaret J. Curry
Danville

Paul DeBoer
Iowa Department of Public Health
Des Moines

Kay DeGarmo
Iowa's University Affiliated Program
University of Iowa
Iowa City

Laurie Dyer
Iowa Department of Personnel
Des Moines

Emily Emonin
506 E. Buchanan
Fairfield, IA 52556-3812

Dave Greimann
Work Consultants
Ankeny

Paul Greene
Iowa Council for Early
Intervention Services
Waterloo

Angela Hance
Creston

Joni Henderson
Independence

Kathy Herring
On With Life
Ankeny

Linda Hinton
Director, Iowa Association
of Residential and
Rehabilitation Facilities
Urbandale

Roger Hoffmann
University Hospital School
Iowa City

Deborah Hughes
Attorney-at-Law
Cedar Rapids

Delbert L. Jensen
St. Ansgar

Karen A. Johnson
Davenport

JoAnn Kazor
Department of Human
Services
Des Moines

Geoffrey Lauer
Regional Brain Injury
Association
Iowa City

Bonnie Linnquist
Department for the Blind
Des Moines

Janet Mapel
University Hospital School
Iowa City

John A. May, MD
Des Moines

Beverly J. McClung
Mason City

Brenda Moore
Child Health Specialty Clinics
Iowa City

Sue Pearson
Brain Injury Consultant
Special Education
Department of Education
Iowa City

Sidney Ramsey
Iowa Health System
Des Moines

Esthyr Ropa
Division of Rehabilitation Ser-
vices
Department of Education
Sioux City

Theodore Wells
Iowa City

Mary Schertz
Early Intervention
Dept. of Education
Des Moines

Janet Shoeman
Department of Human Services
Des Moines

Barbara Smith
University Hospital School
Iowa City

Marvin Tooman, Ed.D.
On With Life
Ankeny

Robert Vander Plaats
President & CEO,
Opportunities Unlimited
Sioux City

Theodore Wells
Iowa City, IA 52246

Debra Westfold
Iowa State Association
of Counties
Des Moines

Beth Zaug
RESCARE Inc.
Ottumwa

Table of contents

Introduction	1
1. Who are the people with brain injuries in Iowa?	3
2. What is the health status and well being of Iowans with brain injury?	10
3. What array of services should be available for Iowans with brain injury?	19
4. Does Iowa have the needed array of services available in a coordinated comprehensive family-centered system?	22
5. Is the array of services accessible to survivors and their families?	29
6. Is the system meeting the needs of survivors and their families?	38
7. What can be done to improve Iowa's services and supports for people with brain injury and their families? The Iowa Plan for Brain Injury	43
References	47

Introduction

Coming Into Focus presents a needs assessment related to Iowans with brain injury, and a state action plan to improve Iowa's ability to meet those needs. Support for this project came from a grant from the Office of Maternal and Child Health to the Iowa Department of Public Health, Iowa's lead agency for brain injury. The report is a description of the needs of people with brain injuries in Iowa, the status of services to meet those needs and a plan for improving Iowa's system of supports.

Brain injury can result from a skull fracture or penetration of the brain, a disease process such as tumor or infection, or a closed head injury, such as shaken baby syndrome. Traumatic brain injury is a leading cause of death and disability in children and young adults (Fick, 1997). In the United States there are as many as 2 million brain injuries per year, with 300,000 severe enough to require hospitalization. Some 50,000 lives are lost every year to TBI. Eighty to 90 thousand people have moderate to acute brain injuries that result in disabling conditions which can last a lifetime. These conditions can include physical impairments, memory defects, limited concentration, communication deficits, emotional problems and deficits in social abilities.

In addition to the personal pain and challenges to survivors and their families, the

financial cost of brain injuries is enormous. With traumatic brain injuries, it is estimated that in 1995 Iowa hospitals charged some \$38 million for acute care for injured persons. National estimates offer a lifetime cost of \$4 million for one person with brain injury (Schootman and Harlan, 1997). With this estimate, new injuries in 1995 could eventually cost over \$7 billion dollars.

Dramatic improvements in medicine, and the development of emergency response systems, means that more people sustaining brain injuries are being saved. How can we insure that supports are available to this emerging population? We have called the report *Coming into Focus*, because, despite the prevalence and the personal and financial costs to society, brain injury is poorly understood.

The Iowa Department of Public Health, the Iowa Advisory Council on Head Injuries State Plan Task Force, the Brain Injury Association of Iowa and the Iowa University Affiliated Program have worked together to begin answering this question. A great deal of good information already existed. This project brought this information together, gathered new information where it was needed, and carried out a process for identifying what needs to be done in Iowa, and what the priorities will be.

The needs assessment set out to answer the following basic questions:

1. Who-are the people with brain injury in Iowa?
2. What is the status of their health and well being?
3. What array of services should be available for people with brain injuries?
4. Does Iowa have the array of services available in a comprehensive, coordinated family-centered system?
5. Is the array of services accessible to people with brain injury and their families?
6. Is the system effectively meeting the needs of people with brain injury and families?
7. What can be done to improve Iowa's services and supports for people with brain injury?

To answer these questions, the project used a variety of existing resources. These are listed as references at the end of the document, but included the following important pieces:

Iowa Advisory Council on Head Injuries, Annual Report 1996

Traumatic Brain Injury Rehabilitation Database, Iowa Department of Public Health

Central Registry on Brain and Spinal Cord Injury Annual Reports, 1994, 1995, 1996
Iowa Department of Public Health

Life After Brain Injury, Iowa Department of Public Health

Survey by the Brain Injury Association of Iowa

Training needs survey
Iowa University Affiliated Program

Department of Education Survey
of AEA Brain Injury Teams

In addition to working with existing documents, the project funded an extensive survey of both providers and consumers. The survey was conducted by Hoyt-Mack and Associates, of Ames Iowa. Hoyt-Mack worked with the Advisory Council on Head Injuries, the Iowa Dept. of Public Health and the Iowa University Affiliated Program to develop the surveys.

The needs assessment portion of this document was designed to answer questions that would lead to a solid plan for improving the service delivery system to people with brain injury in Iowa. It was also designed to be understood by a wide variety of audiences, including those that may be unfamiliar with issues surrounding brain injuries.

In August and September of 1998, The State Plan Task Force of the Iowa Advisory Council on Head Injuries met to review the needs assessment and to use it in developing a state plan.

Neither the needs assessment or the plan are intended to be permanent fixtures. Both should be reassessed on a regular basis but they provide an important place to start.

We hope this document will help bring the needs of people with brain injuries and their families into focus, and provide a map for collaborative efforts to improve their quality of life.

1. Who are the people with brain injuries in Iowa?

*We need a greater understanding of what brain injury is
and its lifetime effects so survivors and families
don't have to explain it all the time.
—Person with brain injury*

The tragedy and challenge of brain injury can occur to any individual, any family at any time. This year, it will happen when an 80 year-old grandmother falls at home, a six-year-old boy riding a bike without a helmet hits a fence, a teenaged girl is thrown from a horse, a baby is shaken by an angry parent, a middle-aged father is rescued from drowning, a promising medical student falls asleep at the wheel of his car. For every incident, lives are changed and begun again. This section will present the statistical picture, to the extent it is known, of brain injury in Iowa: The who, how and where.

Defining brain injury

Nationally and in Iowa, there are both major and minor variations between laws, agencies and even within the same agency in how brain injury is defined. Some of the variations are efforts to define brain injury in a way that makes it possible to quantify with some degree of accuracy. For example, restricting a definition to external trauma makes it easier for hospitals to participate in Iowa's brain injury registry, which requires reports on all

persons hospitalized with brain injuries within 45 days of the quarter in which the individual is discharged, transferred or pronounced dead. But a definition of brain injury is not just a diagnosis, it can also be a key, or a barrier, to funding streams and services.

The definition used in the federal grant application for this project is: *Traumatic brain injury means an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include injuries caused by anoxia due to near drowning.*

The definition used for determining eligibility for the Iowa Medicaid Home and Community-Based Waiver Program for people with brain injury uses a broader definition than the one in the code: *Brain injury means clinically evident damage to the brain resulting directly or indirectly from trauma infection, anoxia, vascular lesions or tumor of the brain, not primarily related to degenerative or aging processes, which temporarily or permanently impairs a persons physical, cognitive or behavioral functions.* The waiver definition

then goes on to list 43 diagnoses from the 9th International Classification of Diseases (ICD-9) that involve injury to the brain. This definition excludes spinal cord injuries from its definition.

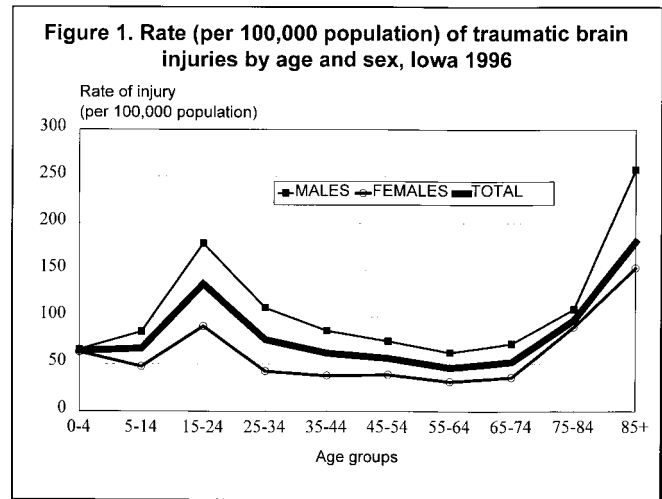
Who

Since 1990 the Iowa Department of Public Health has provided a yearly report on Traumatic Brain Injuries (TBI) in Iowa. (Schootman and Harlan 1996, 1997, 1998). These injuries are identified through the International Classification of Diseases 9th Edition, which is used by medical facilities in billing.

The Iowa report combines data from several sources: The Iowa Central Registry for Brain and Spinal Cord Injuries; ten large Iowa hospitals; death certificates and hospital discharge data. Following the end of each calendar year, hospitals sending in data receive a letter inquiring about additional injuries meeting the inclusion criteria. Letters are also sent to hospitals not sending data. This letter asks the hospital to confirm that no traumatic brain injuries were reported. In a recent study, the completeness of TBI reporting was assessed using four different data sources: the trauma system registry, the paper forms that were received, the hospital discharge database, and death certificates. It was found that when including all four databases, only two percent of reportable TBIs were not reported. Overall, Iowans aged 85 and older were most likely to be missed of any age group.

In 1996 a total of 2205 cases of traumatic brain injuries were identified, three more than

in 1995. This is a rate of 77 per 100,000, the equivalent of a traumatic brain injury every four hours in Iowa. A total of 265 Iowans died of these injuries, 75 less than in 1995. This is in line with national statistics on brain injury death rates of 110 per 100,000.



The rate of TBI for males is twice the rate for females in Iowa, which corresponds roughly to national figures. Nationally, death rates of men from TBI are 3 times that of females (Kraus, 1996). This difference is assumed to be connected with risk-taking behavior in men and occupational hazards that are more common in men.

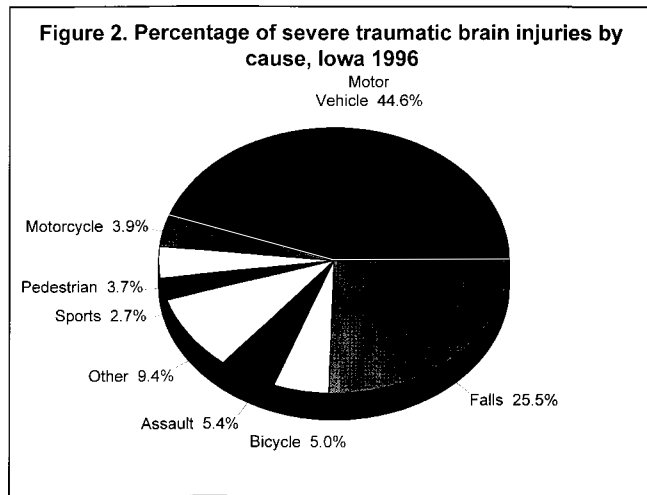
Age is a significant factor in occurrence of TBI. Males over 85 have by far the highest incidence of TBI, with a rate of 250 per 100,000, while females in that age group have a rate of 150 per 100,000. The second highest group is males in the 15-24 age group, with approximately 175 per 100,000.

National statistics indicate that people who have one brain injury are at greatly increased

risk for sustaining additional brain injuries. After the first injury, risk for a second is three times greater than for the general population, and after a second brain injury, a third injury is 8 times more likely (Fick and Petty 1997).

Causes

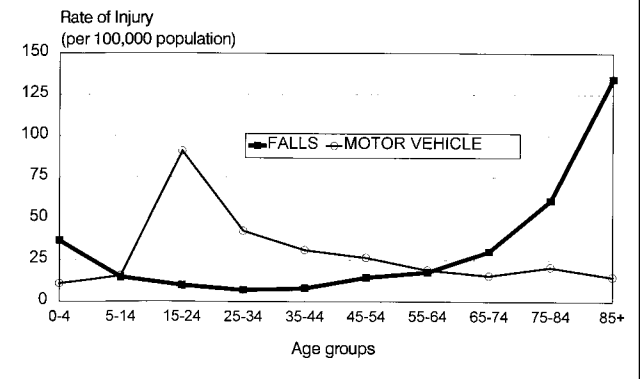
The two leading causes of traumatic brain injury in Iowa are motor vehicle crashes and falls. Motor vehicle crashes accounted for 44.6% of TBIs in 1996, which is below the national rate of 50%. Fifty-four percent of Iowans in automobile crashes that resulted in nonfatal brain injuries were not wearing seat belts at the time of the crash. Falls are the second leading cause of TBIs in Iowa, at 25%, which is above the national



rate of 20% (Brain Injury Association, Inc./ USA, 1997). Iowa's high population of elderly people probably accounts for this difference with 42% of those falls occurring in people over the age of 65. Children from birth to four have the next highest rate of brain injuries from falls, 36 per 100,000. For every age group, females were more likely to be injured from falls than males. Brain injuries caused

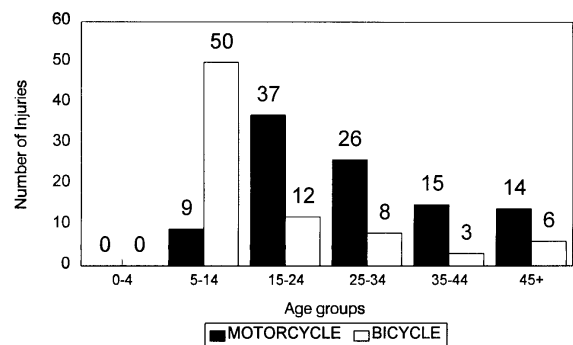
by falls are expected to increase as the percentage of elderly people in Iowa continues to grow. In its 1994 report, the Iowa Department of Public Health had a special focus on falls among the elderly. TBIs from falls among the elderly were at almost the

Figure 3. Rate (per 100,000 population) of traumatic brain injuries for falls and motor vehicle crashes, Iowa 1996



same rate of TBIs from motor vehicle crashes in the 15-24 age group. It was also noted that a high percent of brain injuries from falls in the elderly resulted in death. Of all fatal fall-related brain injuries in Iowa that year, 75% were in people over 65. While children may receive brain injuries falling from playground equipment, chairs or trees, the elderly are more likely to sustain brain injuries falling down stairs. TBI is only part of the public health risk of falls. Falls cause a high level of

Figure 4. Frequency of motorcycle and bicycle-related traumatic brain injuries, Iowa 1995



disability and even death as a result of hip fractures and other injuries.

Bicycle crashes account for the next, but much smaller number of traumatic brain injuries, at 5%. Five to 14-year-olds account

for 58% of the bicycle injuries. Eighty-four percent of those injuries were people not wearing bicycle helmets.

A summary of all causes of brain injury by age follows.

Cause	0-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
Animals	2	5	5	0	0	3	0	0	4	0
Assaults	11	1	31	35	28	6	2	2	1	1
Bicycles	2	64	15	8	11	4	1	2	2	0
Falls	71	61	40	28	35	47	42	59	92	82
Motor Vehicle	21	64	375	173	135	86	45	35	31	9
Motorcycle	1	1	23	19	19	11	8	2	0	1
Other/Unk	10	27	29	32	33	23	11	12	15	13
Pedestrian	5	36	9	9	6	4	0	6	1	4
Sports	1	17	32	5	2	0	1	0	0	0
Total	124	276	559	309	269	184	110	118	146	110

Where

The incidence and cause of brain injury vary across the state of Iowa. Iowa is among the ten states with the highest percentage of rural residents (U.S. Census 1990). In their 1995 report of TBI statistics, the Iowa Department of Public Health (Schootman and Harlan, 1997) did a special focus on rural and urban differences in incidence and cause of TBI. To look at these differences, they classified Iowa's 99 counties according to population per square mile. Then they looked at incidence statistics based on this classification. The overall picture is that the rate of TBI per 100,000 population is highest in the most rural and the most urban counties, although the rural counties were the highest. However, the *fatality* rates for TBI were highest in the most rural counties and progressively lower with increased population. The differ-

ence in the fatality rates was in the fatal injuries involving motor vehicles. Fatal falls and assaults were actually higher in the more urban areas.

Most of the contrast is between the 21 most rural counties and the rest of the state. These counties have some important defining characteristics. Typically there is no community

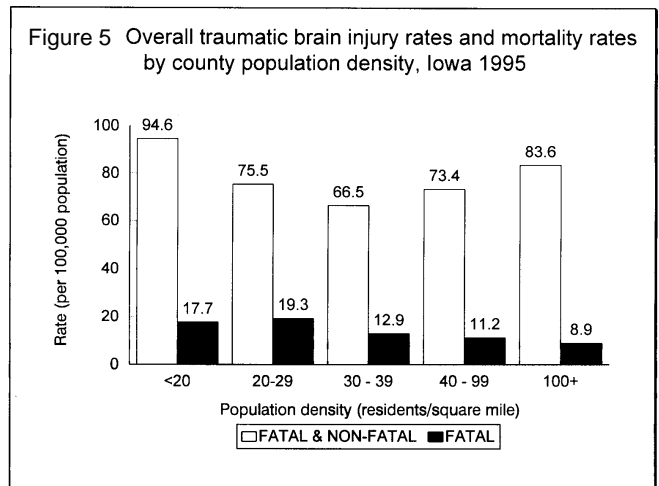


Figure 6 Traumatic brain injury rates by cause and county population density, Iowa 1995

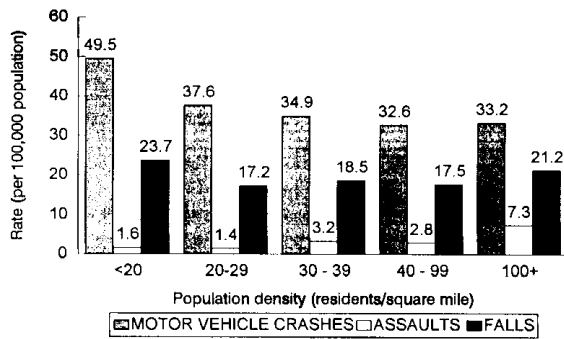
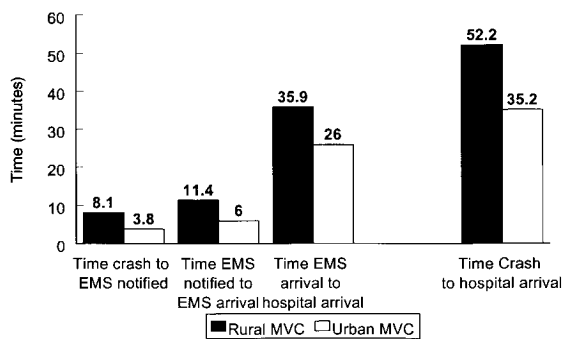


Figure 7 Emergency medical response (EMS) times by rural and urban location of motor vehicle crash (MVC), United States 1995



over 5,000 anywhere in the county, and usually they are not adjacent to larger population centers. They are likely to have a higher proportion of unpaved roads. These are also areas that are more distant from healthcare facilities, particularly ones well suited to manage trauma.

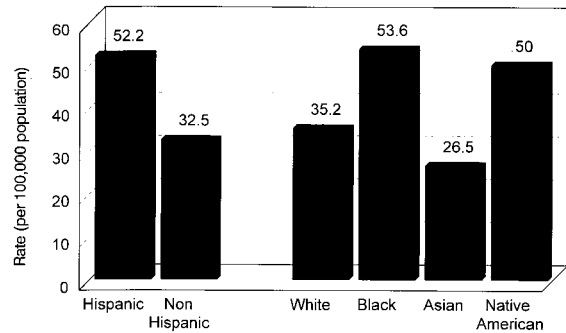
Minorities

Compared to other states, Iowa's minority population is very small. The largest minority group in Iowa is African-American. The 1990 National Census reported under 2% of Iowans as African-American (black) while

reporting 15% nationally. The total of all minority populations in Iowa is only 5%.

Figure 8

Rate of traumatic brain injury by Hispanic ethnicity and race, Iowa 1995



NOTE: About 50% of Hispanic ethnicity and race are unknown

Although based on small numbers, rates of TBI in Hispanic, black and Native Americans are higher than in white and nonhispanic populations which corresponds with national estimates. However, 50% of the reports in the registry have no identification of race or ethnicity.

Prison Population

The connection between brain injury and violent and/or criminal behavior is not a new area of research, but has become of more interest in recent years. Many studies have found correlations between violent crime and presence of brain injuries in the offender, and some researchers even maintain that very high percentages of people on death row have actually sustained neurotrauma. Others argue that research has not shown whether brain injury is a cause of violent behavior, or whether people with a tendency to violence are more likely to sustain a brain injury.

Little is known about the number of prisoners with head injury in Iowa. Rate of violent crime in Iowa is almost half the national average, and the number of prisoners per 100,000 population is only 60% of the national average (Stephan and Memola, 1997). Prison officials in Iowa acknowledge only a "handful" of prisoners with diagnosed brain injury. Medical classification personnel in the Iowa prison system have concerns about the effect that a "vague relationship between brain injury and socially unacceptable behavior" might have in criminal prosecution.

Community based corrections personnel report that prisoners with brain injuries in community settings face the same kinds of problems in obtaining appropriate residential and rehabilitation services, and funding issues, that the non-criminal population faces. There is little available that is appropriate, and funding is limited.

Agency Data

Estimates from the Iowa Department of Education on students with brain injuries are low, available for a limited number of years, and not considered very accurate. There are currently 70,000 Iowa students in special education, but as the department no longer categorizes them by diagnosis, figures on students with brain injury are not available. In the 1994 count, when there was still identification by disability type, there were 117 students identified as brain injured. This is considered by some to be a low estimate, since many students with brain injury prob-

ably were identified under other primary diagnoses such as behavior disorder. The IDPH census figures for 1996 show 879 individuals under the age of 22 were hospitalized with a brain injury. It should be assumed that many of these young people returned to the public schools after their injuries.

As the state education consultant for brain injury suggests, the data probably best represents how little we know about the true numbers of students with brain injury in special education.

Iowa's Division of Vocational Rehabilitation identified 370 individuals on the division's active case load of 11,797 (May, 1998) that have brain injury identified as one of their disabilities or disabling conditions. This number does not include anyone who would currently be on the division's waiting list, or who was served in the past, but who currently does not have an open case file.

The Iowa Department of Human Services estimates that of the 8478 individuals who are funded or receiving services through the department's programs, 300 are individuals with a brain injury. Services that may be included in this list include state Medicaid Waiver services, individuals receiving juvenile services, and individuals under the age of 18 who are in residential settings. Individuals who are over the age of 18 are the responsibility of their county of legal settlement. Accurate figures for the numbers of individuals with brain injury that are receiving services through the county funding system in any or all of the 99 counties are not available.

Statistics on the Total Iowa Population with Brain Injury

Several factors contribute to the difficulty of getting accurate estimates of the number of people with brain injury living in Iowa. Among them are the varying definitions of brain injury, the difficulty of counting people who are not hospitalized for their injuries, misclassification, and the difficulty of identifying people who are not in “the system.” (Kraus and McArthur, 1996).

After hospitalization, many people with brain injuries leave the health and human services delivery system. And many people with brain injury are never hospitalized. Since there is no central registry for less severe brain injury, estimating a total number of people in Iowa with brain injuries is challenging. Underestimating the resources needed would not be

helpful, but neither would alarming the public with high estimates that include people who may in fact need little or no support. An estimate is that 7 to 8 thousand Iowans per year incur a brain injury (Schootman and Harlan, 1996). While most of these did not result in hospitalization, the injuries often have major effects on survivors and their families.

A very rough national figure suggests 1 in 220 people, or 130,000 Iowans, live with the effects of a brain injury (Kraus and McArthur, 1996).

In this section, the broad population parameters for Iowans with brain injury have been described. In the next section, the report offers a view of how some of these Iowans are doing.

2.

What is the health status and well being of Iowans with brain injury?

*I don't know yesterday.
-Iowan with brain injury*

Although brain injury is the leading cause of death and disability among children and young adults in the United States and in Iowa, it is also one of the most hidden and least understood disabilities. After hospitalization, often with no community service structure to move in to, people with brain injury return to their families and homes and try to pick up their lives. One family has compared it to “walking the plank.” In recent years, there has been a growing interest in these survivors, in their families and in the challenges of life post-injury.

A number of sources were used to help bring into focus a picture of how Iowans with brain injury are doing: What are the long-term effects of the injury? Where are they living? How is their health and well being? The Iowa Department of Public Health’s most recent report on brain injury (Schoutman and Harlan, 1998) offers information on the severity of injuries of those who have been hospitalized with traumatic brain injury. The Iowa Department of Public Health also (Schoutman, 1998) recently published a report on a survey of over 400 Iowans who

were a year to a year and a half post brain injury which has provided important insights into the immediate return to community life. As part of this MCH project’s needs assessment activities, Hoyt-Mack Research Associates, of Ames, Iowa, conducted in-depth telephone interviews with a group of 100 consumers and/or family members, representing people aged 7 to 73 with a median age of 35. Fifty percent of the people in this group had received their injuries ten years ago or more, which offers a long range look at the lives of survivors. William McMordie of Iowa Methodist Medical Center in Des Moines conducted research (McMordie et al, 1989) on the employment status of some 177 Iowans after a traumatic brain injury which provides a framework for looking at the employment status of survivors in both the Life After Head Injury and telephone surveys.

Where Do They Live?

In Iowa’s 1996 TBI census, 76 percent of Iowans with TBIs who were admitted as inpatients were discharged to their own

homes (Schootman and Harlan, 1998). Eight percent were discharged to a residential facility (with or without skilled nursing services), eight percent were discharged to inpatient rehabilitation, 5 percent were transferred to another acute care facility, and 2.6 percent died as inpatients. The remainder of the patients had “other” discharges.

The percentage of persons discharged home ranged from 67 percent for falls to 100 percent for TBIs resulting from sports. Seventeen percent of motorcycle-related TBIs required admission to inpatient rehabilitation.

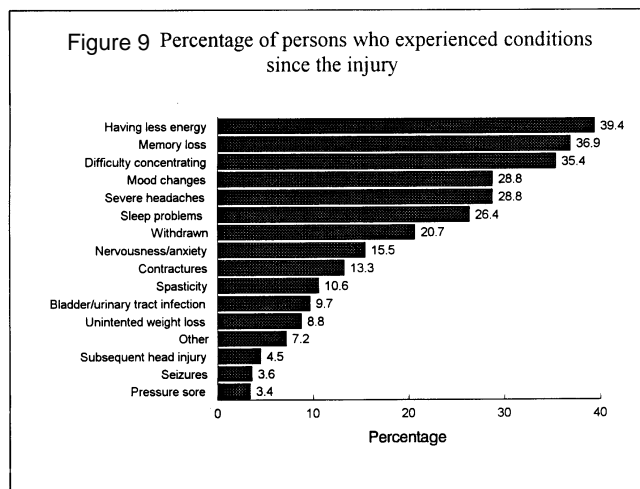
In the one year post-injury follow up study by Schootman (1998), 74 % of the respondents were living with family and 15% living on their own.

In the Hoyt-Mack survey, 30% of the respondents were living by themselves, but half of these, or 15% of the total in the telephone survey, also have someone else who helps take care of things. Over 90% of the time, this person is a relative. The remaining 70% live with someone else, most frequently with parents (35%) other family (46%) or in a group home setting (15%). Just under one-half (48%) report that their living situation changed since the injury. This mainly represents the group who were old enough to be on their own at the time of the injury, and had to move back with family or into a care setting.

The Effects of the Injury

The effects of brain injury were assessed in both the one year follow-up and the telephone surveys. In the IDPH study, 70% of the

surveys were filled out by the survivor, and the rest by a family member. In the telephone survey for adults, 27% of the interviews were done with survivors, 69% were done by a family member and 4% by a family member and the survivor together. The task force from the Iowa Advisory Council on Head Injuries suggested that people with brain injury tend to see less disability in themselves, and to be more positive about their functioning than family members might be. Having both perspectives should be helpful.



In the Schootman study, 70% of the respondents reported developing one or more conditions since the injury. Having less energy or getting tired more quickly, memory loss and difficulty concentrating were reported most frequently. Ninety-eight percent of those with severe brain injuries reported a problem, while 69% of those with mild brain injuries did. For those with severe brain injuries, difficulty concentrating was the most frequently reported problem. For people with moderate and mild injuries, having less energy was the most often reported problem.

The telephone interviews used broad areas of concern as prompts in the interviews, but all participants were asked for additional comments as well. The areas covered physical difficulties, memory difficulties, difficulties organizing activities, difficulties making decisions, emotional difficulties and learning difficulties.

Physical Difficulties

Most of the telephone survey respondents (81%) reported one or more physical difficulties. Eighty-three percent of the family members mentioned physical difficulties, and 73% of the people with brain injury, a difference not large enough to be considered statistically significant. Most common among these physical difficulties were trouble walking, including balance difficulties or walking with an uneven gait, poor coordination, and difficulties with speech. A few respondents mentioned trouble swallowing, incontinence, pain, vision limitations, weakness, and limited or no hearing. A small proportion of the respondents reported more severe physical limitations requiring full-time caregivers. Those whose injuries had occurred since 1990 were a little more likely to report physical disabilities than the group injured before 1990, but it was not a statistically significant difference.

Memory Difficulties

Nine of every ten respondents in the telephone survey (92%) report having memory difficulties. Most common, by far, are short term memory problems, reported by 79% of those reporting memory problems. Some examples of specifics:

- I don't know yesterday
- He has trouble remembering appointments, medications, things like that
- She has trouble with names, gets confused about what to call things
- I can't recall telephone conversations after I hang up
- Does laundry, can't recall if put soap in
- I had a meeting on a calendar one night, another the next night, and I went to the wrong one

Many report needing to use memory aids to help with this short term memory problem.

- Has to write stuff down to help remember
- Has to use a list to remember
- If don't write it down, he will not remember it

Respondents also report that memory problems may be worse at some times than others.

- Thinking slows down when he gets tired, works very hard at memory
- Memory problems, especially when tired

Organizing Daily Activities

Nearly two-thirds of the telephone survey respondents (64%) report that they have problems organizing daily activities. Fifty-one percent of those reporting this problem say it is related to the short term memory limitations mentioned above:

- Has to use datebook to schedule and journal to remember what she did
- Tell him to do chores and he forgets.
- Sequencing events is difficult, can not have two appointments in one day
- Uses an appointment book. If something is not in it, he doesn't do it

Twenty-two percent of those reporting this problem speak to a general need for assistance or dependence on others for organizing and scheduling activities. This also includes children who are too young to be expected to organize their own activities yet. Comments included:

- He does not organize daily activities.
- Has to be directed by others
- Has to get up early to be ready to do things, needs direction
- Group home managers must check on him to see if he has planned his meals
- Has to have day scheduled and written down for him
- Each day has to be scheduled on paper

Other examples include getting sidetracked easily and problems with motivation.

- Trouble taking the initiative
- Trouble keeping appointments
- Low motivation, trouble setting goals
- Tries to write down things in list, but if not in right order she has trouble
- Needs a plan to get out of bed each day
- When he is having a bad day, it is difficult to schedule

Making decisions

Three-fourths of the telephone survey respondents (75 %) report difficulties with making decisions. Survivors were significantly less likely to report difficulties with decisions than family members. Sixty percent of the survivors mention this problem, but 79% of the family members do. When asked for specifics, about one third of the respondents (32%) mention problems reaching closure.

- Difficulty with decisions as simple as when he is through with lunch

- Can't decide what to order in a restaurant
- Trouble buying clothes
- Everyday decisions, such as picking a movie or buying clothes
- Takes him a long time
- Would get dressed, then change a few times
- Indecisive or takes a long time to decide
- Slower on more complicated decisions

About one in five (21%) of those mentioning decision making problems refer to occasional problems with decisions that are not well-advised or realistic.

- Forgets limitations, not making decisions based in reality
- Poor decisions, takes SS money and uses it for gambling
- Sometimes makes irrational decisions
- Trouble making social decisions and is often inappropriate to them
- One time makes rash decisions, another time can not make a decision

Other examples include difficulties associated with disagreement on decisions, indecisiveness or lack of confidence in decisions, trouble evaluating the situation to make a decision, and maintaining focus.

- Does not always accept spouse's rationale
- Hard to deal with rejection of what he has decided on
- Lacks confidence in decisions that she makes
- Calls home frequently to get advice on what to do and how to do things
- No initiation
- When tired, gets easily frustrated with having to make decisions
- Has trouble keeping focused on longer questions.

- Does not always attend to things long enough to make a decision

Emotional difficulties

Just over three-fourths of the telephone survey respondents (76%) report some type of emotional difficulties resulting from the brain injury. About one fourth (26%) report some instances of heightened or accentuated emotional responses to situations:

- More sentimental, cries easily
- Is more sensitive to comments from others
- Sometimes more sensitive about things
- More sensitive to things
- Cries easily

In 20%, this heightened response takes the form of anger or frustration.

- Anger outbursts, yells
- Reacts with anger more rapidly
- Shorter fuse and explosive anger
- Anger outbursts when he gets frustrated
- Is more irritable, but has learned to control it

On the other hand, some 12% of the respondents indicate a lower affective response, less emotional reaction.

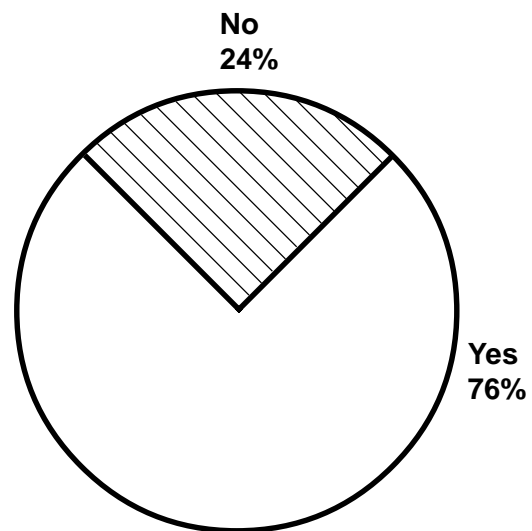
- Little more emotional, especially when tired
- Flat affect, does not express emotions
- Shows no emotion, no animation

Ten percent report mental health concerns, particularly with respect to depression

- Has some problems with depression
- Has threatened suicide
- Some self-esteem and self-confidence issues

- Many mood swings
- Depressed, on Prozac now and that has helped
- Very moody and easily depressed

Fig. 10 Experience Emotional Difficulties



Learning difficulties

More than eight in ten of the telephone survey respondents (84%) report having learning difficulties as a result of the brain injury.

Although not statistically significant, in contrast to some of the other reports on problems, more people with brain injury (93%) named this as a problem than family members (81%). Forty-three percent of the learning difficulties named were memory related.

- Can not remember what he reads
- Should know, by now, the safe way to get out of a chair, but forgets
- Could not handle to go to school now, can't remember what she needs to
- Forgot much of what he had previously learned

Nearly a third (32%) report that the person with brain injury can learn, but that it takes longer to acquire information and may require alternative forms of learning.

- Has to repeat tasks to retain them
- Takes longer to learn
- Needs to review things to get the same amount of recall as others
- Can learn, but just takes longer.
- Has to study something 3 to 4 times to learn it
- Gets more information from video than from reading
- Needs tasks broken down in order to do them
- Learns better visually

Twelve percent note that focus and attention issues effect learning.

- Attention problems, mind tends to wander
- Attention problems, easily distracted by noise
- Can only focus a short time

Work

The high number of survivors reporting problems with memory, concentration and emotional problems also supports research showing that returning to work post-injury is a problem. In 1989, William McMordie of Iowa Methodist Medical Center in Des Moines studied the work situations of 177 Iowans who had sustained head injuries (McMordie et al, 1989). This survey was mailed to members of the Iowa Head Injury Association and respondents included 138 males and 39 females over the age of 19. The authors noted that a sample coming from a support group might be biased somewhat toward people with more serious problems.

Over half of the study group reported being in no work at all. The other half included people in volunteer, part time, work training and sheltered work, with only 17 of the group being involved with regular full time employment. The study also looked at problems people were having related to the brain injury. Reports of learning problems, motor problems and ambulation difficulties were significantly higher in those who were not working as compared to those who were able to be competitively employed. It was also noted that people over the age of 40 had the hardest time returning to work, while teens and people in their twenties or thirties were about the same.

McMordie's study was in part an answer to research in England that showed most people with head injuries were able to work. While McMordie's Iowa study shows opposite results, the author points out that the British work was done in the late 1960s. ***"The most important factor is that persons who would have died from their head injuries 20 years ago are surviving today because of improved medical technology. Recent studies on return to work after head injury does not suggest that most people will be able to return to work after sustaining a severe head injury,"*** McMordie explains. The McMordie work itself is now ten years old, and the situation may be of even more concern today.

The Life After Brain Injury survey (Schootman 1998) supports McMordie's conclusions. Although 46% of the respondents reported being employed, only about half of those were actually in either full or part time work performed independently. The rest were in sheltered work or training or supported work settings.

In the telephone survey group, a little over one third of the survivors (34%) currently work. The types of employment mentioned ranged from professional/white collar type occupations (e.g., financial planner, rehabilitation counselor) to more service and laborer types of work (e.g., cleaning worker, store clerk, cafeteria aide), skilled and semi-skilled work (e.g., mechanic), and part-time workers. Some respondents also reported being involved in voluntary work. While many of the respondents mentioned some degree of limitations, some were still involved in work that requires more physical activity (e.g., farmer). Among those who work, 38 percent are part-time workers (mostly in service positions), 24 percent are service and laborer positions, 24 percent are in skilled and semi-skilled work, and 14 percent are in professional and white collar positions.

For the people with brain injury who were not working, the two primary reasons (representing over half of those not working) were physical (e.g., speech limitations, physically unable to perform work) or mental (e.g., memory problems) limitations directly related to the Traumatic Brain Injury. A few respondents indicated that they had initially tried to return to work but had to quit or were fired due to problems with aspects of the job. In total, about 9 percent of the persons not working were looking for, but unable to find, employment.

Almost one-fourth (23%) of the persons not working were either too young to work or were still in school.

Changes in lifestyle

Not surprisingly, the telephone interviews showed nearly all (93%) of the people with brain injuries had to make many changes in their lifestyle because of the injury. Many examples highlighted changes in physical or mental abilities:

- Takes a nap after dinner to keep from getting too tired
- Lack of independence, has to have a care-giver with him all of the time
- Was very athletic, now cannot be
- In a wheelchair, can't drive
- Can not drink, alcohol counteracts medications
- Can not drive
- No longer drives

About one in five comments centered on implications for social and personal relationships:

- Not able to maintain long-term romantic relationship
- Used to be social, now very isolated
- Wife filed for divorce
- No social life
- Don't go out much with other people
- Does not leave the house much
- Divorced after injury
- Spouse had to help a lot, hard to be independent
- Lost all of his friends
- Hard time with conversations
- Husband left her
- Does not like being around people anymore
- Has to be forced to go out and do things
- Used to date a lot, now does not even think about relationship
- Socialization is very difficult

- Has not dated anyone since the accident
- Worries if she could ever be in a long term relationship
- No one to socialize with

Not being independent in daily routines also was mentioned:

- Grandmother came and took care of her and the children
- Can't work and lives in public housing
- Was previously independent, now lives with parents
- Used to live in nice house, now in an apartment
- Could not finish school, lives with parents

Changes in Activities

Eight out of ten of the telephone survey respondents (79%) mentioned activities they could no longer do. Most comments focused on sports and other physical activities requiring high levels of energy and coordination.

- Used to be athletic, but can not run anymore
- Can not participate in sports
- Can not dance
- No athletics
- Can't hunt because he can not walk too well
- Can not swim
- Sports, baseball, softball
- Can't really run
- No sports, uses a cane to help with balance

A number of respondents noted the inability to drive. Others mentioned the need to avoid crowds, groups, or situations where there was a lot of noise.

- Does not like being in crowds
- Group situations are very difficult
- Can't handle loud crowds
- Does not like loud noises
- No crowds or any situation that involves stress

There were also a number of more specific changes in activities ranging from minor to major restriction.

- Can no longer do woodworking
- Balance is bad, can't do activities like mowing or cleaning out the tub
- Can't do volunteer service organizations because of fatigue
- Has trouble playing with kids because of hand-eye coordination
- Can not go to long events, problem with attention span
- No strenuous activities, tires easily
- Just about everything
- Cannot turn pages to read
- Can not do anything that raises body temperature

Family Life

Brain injuries don't happen just to an individual, they happen to a family. Families are the major service provider for people with brain injuries when the hospitalization is over. The health and well being of the family is also affected by the injury and is a critical part of any needs assessment.

Most (87%) of the telephone survey respondents report that their family changed in some way as a result of the brain injury. As noted in the changes in lifestyle responses, these changes sometimes included the loss

of a marital partner and in other instances marital stress.

- Divorced right after TBI. Can't visit children
- Went through two marital therapists and was separated for six months
- Some initial conflict, lots of 'close calls'

Other family members also showed signs of stress.

- Early negative reactions from siblings, took too much of parent's time
- Having an adult child at home has caused strain on parent's relationship
- His inactivity and loss of interest has required some adjustment by other family members
- Younger sister irritates him due to her lack of understanding
- Children are always throwing memory problems in her face
- It has shook everyone up, she now has a different family role
- Was the oldest, has been a tough adjustment for younger siblings
- Father has not educated himself about TBI, can not handle it

However, in addition to comments about problems and stresses, many also refer to a family coming together, making the needed adjustments, and sometimes getting closer through this experience.

- They have had to adapt, but have been very understanding
- Family had to move to help with his needs
- Moved when could to be closer to family for help
- Mother took early retirement to work with him
- Everyone came together to help

- Sister got involved in TBI associations
- Family has adjusted to TBI, no education for families, had to learn slowly
- Mom became involved as a special education consultant, relationships are good
- Family has adjusted and is very supportive
- Both good and bad, was hard on kids, but now family closer together
- Wife had to go back to school and get a job to support family
- Have been supportive and traveled a lot to visit while in hospital
- Family has to be there for him around the clock
- Family is a lot closer now
- They have changed their way of thinking about TBIs
- Family became very involved in brain injury association

Summary

It is clear that the vast majority of people with brain injuries have some long term problems as a result of their injury. Memory loss, problems with concentration, headaches, ambulation and other motor problems. Work, school, family and other relationships — the things we look at to assess our quality of life— are strongly effected by these ongoing problems. The survivor and family struggle to build and maintain a good post-injury life.

What can help with rehabilitation and long term adjustment for these survivors and their families? Section 3 looks at the array of services and supports that should be available in a quality state system for people with brain injuries.

3.

What array of services should be available for lowans with brain injury?

*Basically, I lost almost everything for about five weeks, and I went home to try to start over with everything.
—lowan with a brain injury*

People living with the effects of a brain injury have been identified as an emerging and poorly understood population, relative to people with other kinds of disabilities. Our understanding of the array of services needed to help with their rehabilitation and long-term support is also emerging. The immediate medical treatment for the person experiencing a traumatic brain injury is fairly well established. But what follows is much less well understood. The degree of recovery eventually achieved and the process of recovery varies from individual to individual; although physical impairment is common, the more severe disabling effects of brain injury are in cognition and behavior. For many, these effects call for life long change, adjustment, and support. In addition, because some of the recovery is gradual and spontaneous, we have less scientific understanding of what kind of rehabilitation is effective.

As brain injury survival has increased due to medical technology and delivery, concern about the disorganized development of reha-

bilitation services has also grown. Over ten years ago, the federal government funded a number of demonstration programs to develop models for a quality continuum of services that should be available for persons with traumatic brain injury (Ragnarsson, et al. 1993)

The services identified for that model included:

- Emergency medical services with sophisticated field evaluation and transportation
- Acute comprehensive rehabilitation services with a complete interdisciplinary team, including vocational and educational representation
- Long term interdisciplinary rehabilitation follow-up services and assessment including medical, social, psychological and vocational.

Other important elements in the model continuum included behavior modification pro-

grams, rehabilitation services at home, case management and community living options.

There are many different approaches to identifying the range of services to meet the needs of people with brain injury. The model program listed above named broad areas of service. Other approaches make finer distinctions in services. In a recent rehabilitation survey in Iowa, (UI Injury Prevention Research Center et al, 1997) service providers chose from a much more detailed list of services and supports, 90 in all. The range included specific types of services such as peer counseling and several different kinds of employment service options.

The Service Task Force Report for the Iowa Advisory Council on Head Injuries (ACHI 1996) describes the service needs as follows:

Persons with disabilities, including persons with brain injury, need a flexible set of services and supports so that they may return to living independently and productively. People with brain injury often have cognitive limitations as a result of the injury. These limitations may include problems with memory, attention, planning and judgment. These limitations make it difficult for many Iowans with brain injury to be effective self-advocates for the services they need. As a result, it is extremely difficult for these individuals to access needed services which are often administered through a maze of state departments and local agencies.

The task force guiding the needs assessment for this project was asked to identify the range of services that would be used in surveying providers and survivors in Iowa. The task force first identified ARRAY as a better term than CONTINUUM in describing the range of needed services and supports. *Array* was chosen to get away from the idea that people needed to go through a series of service steps as they progressed. The term array was meant to emphasize the need for choices, given the widely differing needs of people with brain injury. One person might indeed need to move through a series of progressively more independent employment services, for example. But another might need only short-term help with job seeking and interview preparation.

For the provider surveys done for this needs assessment, the Task Force settled on larger categories of services which were based on broad areas of need. They felt with the finer distinctions, there would be less agreement on what the services really involved, especially since the service system specific to people with brain injury is relatively undeveloped in Iowa. Their list included the following:

- Medical services: This includes the initial emergency system and hospitalization as well as out patient services, and community service referral
- Therapy: OT/PT, Speech, behavior therapy, cognitive therapy
- Educational services

- Community living: Independent living training, housing, respite, adult day care, supported living, transportation
- Employment services
- Family or individual counseling
- Case management

A focus group conducted for this needs assessment, as well as a recent survey by the Brain Injury Association of Iowa suggests two other components for the array:

- Information and referral: People with brain injury and their families need to have a service to help them find needed information and resources. This is a

critical service that needs to be part of the array. It is especially important to have at the time of hospital discharge.

- Training/technical assistance: There is little point in developing an array of services, if the people working to provide those supports are not familiar with the special needs of people with brain injury. As the main service providers for people with brain injury, the family too needs to be able to receive training and to take part in training other service providers.

The next section will explore whether all the components of this array are available in Iowa.

4. Does Iowa have the needed array of services available in a coordinated comprehensive, family-centered system?

*Families are the number one provider of services in Iowa
for people with brain injury.*

—Brain Injury Association of Iowa President

*We have literally no services available. There is no information source so that
people can even know what to ask for. The people that certified as brain injury
providers have one day of training. I mean, let's get real here.*

—Rural County Service Coordinator

An appropriate array of services for Iowans with brain injury would include medical services, therapies, individual and family counseling, community living assistance (including transportation), education services, and a variety of supports for employment. To enable people to use these services and supports, you would also need advocacy and information and referral services. Further, to insure that the services met the special needs of people with brain injuries, training is needed for providers, including family members who are currently, and probably always will be, major providers of services and supports.

Is this array available in Iowa?

Many survivors, family members and providers have answered this question with a firm "No!" The consumer and provider telephone

surveys were used to amplify this response, as was a special focus group on service funding attended by providers, state agency representatives, consumers and family members. In addition, we made use of Iowa Compass, a statewide information and referral service that annually surveys disability programs on the populations they serve and the specific services they provide. The provider survey done by the University of Iowa Injury Prevention Research Center, Iowa Department of Public Health and the Governor's Advisory Council on Head Injuries (referred to as TBIRDS) is used, as well as a survey of state agencies done as part of this project (DeBoer 1998).

The information available suggests that providers of the "array" of services do exist in some form in Iowa currently. The provider

surveys (Iowa Compass, Hoyt-Mack and TBIRDS) all ask this question: "Do you provide service X to people with brain injury?" If the provider answers "Yes we do" then they are counted. Currently there is no other way to assess whether a brain injury service exists.

Interviews and anecdotal information suggest that in fact very few of the services identified are geared specifically to people with brain injury. In Section Five we will also be looking at the accessibility issue, which suggests that funding, eligibility and geography play a major role in making services truly accessible.

The State System

The Code of Iowa (225C.23) has recognized brain injury as a distinct disability in the law as follows: *The Department of Human Services, the Iowa Department of Public Health, The Department of Education and its Divisions of Special Education and Vocational Rehabilitation Services, the Department of Human Rights and its division for persons with disabilities, the Department for the Blind, and all other state agencies which serve persons with brain injuries shall recognize brain injury as a distinct disability and shall identify those persons with brain injury among the persons served by the state agency.*

There is a beginning structure for statewide coordination of services for people with brain injury in Iowa. The Iowa Department of Public Health has been designated the lead agency for brain injury. Iowa has a brain injury registry where hospitals are required to report all hospitalizations related to brain

injuries. This is part of the state trauma registry and TBIs are identified through International Classification of Diseases-9th Edition (ICD9) codes.

The Iowa Advisory Council on Head Injury was formed in 1989. It is located in the Iowa Department of Public Health and has 18 voting members as well as ex-officio representatives from other departments in state government. The members are appointed by the Governor and include survivors, family members, advocacy organizations and providers. The Council has two standing task forces, one focused on services and the other focused on prevention, awareness and legislation.

There is currently a Medicaid Home and Community Based Waiver in Iowa for individuals with TBI. In 1998 it will serve 60 individuals who have been in institutional settings and will be expanded to 72 in 1999.

Are the services there?

In the telephone survey of consumers, 50% sustained their injury over ten years ago. Consumers were asked to name services they received, rather than choose from a list of services. Most of the respondents (87%) named at least one service that they were currently receiving. About one-fourth (24%) named just one provider, 14 percent named two, 18 percent named three, 9 percent named four, 9 percent named five, and 12 percent named six. Respondents named an average of 2.6 service providers.

Twelve percent of the respondents only named a support group or groups as service providers. Combined with the 13 percent

who did not name any services, a total of one-fourth of the TBI survivors do not report getting assistance from a formal service provider.

Not surprisingly, given that the study used support groups to recruit a portion of the sample, the most frequently mentioned type of service was a support group (29% of all services mentioned). While this may not be officially recognized as a service by some, it is what survivors and their families thought of most as a service.

The next most frequently mentioned service was disability/SSI payments, 16% mentioning this. Some providers would not see this as a service, but it is what came to mind for many consumer and family respondents. Other services mentioned ranged from very general assistance to specific local facilities. No single type of service represented more than five percent of the named services. There were examples of each of the service “array” categories in their responses. In the Life After Head Injury survey (Schootman 1998), which surveyed consumers a year to a year and a half away from injuries, respondents chose from a list of services. Given how recent their injuries were, it is predictable that various rehabilitation therapies were the most commonly used services.

Two surveys were used in assessing the existence of the service “array” elements in Iowa: The IOWA COMPASS survey and the TBIRDS. The TBIRDS survey sent questionnaires to 299 providers. There were 156 surveys returned, 90 of which said they had brain injury programs. On the TBIRDS survey, some 90 possible services to people with brain injury were included as choices.

The IOWA COMPASS computerized list reports 120 programs that serve people with brain injury, from a data base of disability related entries. This list did not include the 16 AEA head injury teams and 99 Department of Human Services offices in the state. Only seven of these programs report being specifically for people with brain injury, as opposed to including people with brain injury along with other people with disabilities.

Therapy

In the telephone survey, 73% of the respondents received some kind of therapy, with physical therapy and speech therapy being the most common. In the Life After Head Injury survey of recently injured survivors, 35% reported receiving physical therapy, 18% reported receiving occupational therapy and 15% reported receiving speech therapy.

The provider survey done by IDPH shows speech therapy being offered by over half the programs listing people with brain injury as clients, the most often mentioned service of any in the list of 90 some categories. Forty-seven programs mentioned physical therapy and 41 mention occupational therapy.

IOWA COMPASS lists 29 agencies offering specialized therapies for people with brain injuries.

Education

A free appropriate education is offered to all Iowa students until age 22, including those with brain injuries. Iowa has adopted non-categorical special education, so children are

no longer given a label in order to receive services. The 15 Area Education Agencies which provide the special education services to local school districts each have a brain injury team that consults with the schools on students with brain injuries.

While Iowa's universities and community colleges do not appear on any of the survey lists, many now have special offices for students with disabilities and special programs to assist students with learning disabilities. Some of these programs are certainly serving people with brain injuries.

Employment

A third of the respondents in the TBIRDS provider survey report providing job coaching and job training. Twenty-eight percent report providing supported employment services, and 16% reported providing sheltered work.

The Life After Head Injury consumer survey shows 7% received vocational assessments in the year following their injury, and 3% received job training.

Community Living

In the TBIRDS provider survey, half reported providing independent living skills training, 11% reported providing chore services in the community, and 10% reported providing personal assistance in the community. Ten percent reported providing supported community living and 5% reported providing transitional living services. Transportation is an important service for people living in the community, especially in rural areas. Seven-

teen percent of the TBIRDS providers reported providing driver evaluation and driver training programs, and another 25% reported providing transportation services.

Counseling

Eighteen percent of the programs surveyed for the TBIRDS survey reported providing outpatient family counseling related to brain injury, and 20% reported providing outpatient individual counseling. The IOWA COMPASS database lists 18 agencies providing counseling to people with brain injury. The Mental Health Centers of Iowa are a resource available to all Iowa communities, but they are extremely overburdened. In addition, as one provider explained *"We're looking at the experience and the ability of the therapist to deal specifically with brain injury. If I had 5000 therapists in my county, I'd be surprised if I had two who had any experience with people with brain injury."*

In the Life After Head Injury survey, 14.2% of the respondents reported receiving psychological counseling and 5% reported receiving family counseling.

Case Management

To quote one Iowa provider, *"Case management is a term that gets used and abused. Everybody has case managers. Pizza Hut has case managers!"* Case management is a broad term that today often includes the role of carrying out cost management efforts. But the focus group on service funding defined it in family terms: *It's not case management like happens at an HMO, but its having some-*

body to help you weave your way through the system, and that usually today falls on family and friends.

The only case management required in the state for people with brain injury is part of the Medicaid HCBS Brain Injury Waiver which is now only for 60 consumers. Doing case management with people with brain injury is a different experience, according to one person involved with the waiver program.

"I had two case managers tell me that their clients with brain injury were really forcing them to individualize much more than their consumers with mental retardation were. I think part of it was because these folks are adults who remember what they used to be like and have high expectations. They're not going to say OK, just fit me into a program someplace and I'll go on there for infinity."

In the TBIRDS provider survey, almost half of the 90 respondents said that they supplied case management services. IOWA COMPASS lists 9 agencies that say they provide case management services to people with brain injury.

Case management is available for individuals who are eligible for services under other diagnoses such as developmental disabilities or mental retardation if they qualify. Vocational Rehabilitation has case management available to any individual who receives VR services, regardless of the disability.

Training

There is a growing awareness that training is the cornerstone of improving services for

people with brain injury in Iowa. *"It can't be one day training,"* says a county human services coordinator. *"And it's constant staff development because the brain injury from mild to severe, its so specific to the individual that it can't be categorized. It's totally different rehabilitation from what most providers know."*

The Brain Injury Association of Iowa sponsors two conferences per year for individuals, family members or professionals, and there are typically two additional conferences a year that are specifically targeted for families and individuals with brain injury that are sponsored by the association or its chapters.

The Medicaid brain injury waiver program is the only service in Iowa where there is mandated training to become a provider for people with brain injury. Vocational Rehabilitation and the Department of Education have brain injury training offered, but it is not mandated. The Iowa University Affiliated Program has presented three well attended sessions (over 100 average attendees) on brain injury over the Iowa Communications Network and is planning a series for the upcoming year.

Information and Referral

Information and referral is an essential part of the service delivery system. The words of a parent at the funding focus group describe the need for information and referral services:

I am a parent of a nineteen-year-old who had a severe trauma to the head last year following a car accident. We didn't know where to turn or who to talk to. I see all of you government officials here today and I am absolutely amazed that there are so

many people out there who are supposed to be taking care of problems. So far we have found that the system always works against us.

The telephone survey of survivors shows information about services came from a variety of sources. The three most frequently named were case managers or social workers (18%), support groups (17%), and doctor or specialist (14%). Other sources included family members, mass media, self, and word of mouth.

In the TBIRDS provider survey, 33% of the programs report providing information, and 45% report providing referral services.

Advocacy

At the state level, Iowa has a statewide Advisory Council on Head Injury funded by the legislature and designated in the Code of Iowa. The Brain Injury Association of Iowa was founded in 1980 as the second charter chapter of the National Brain Injury Association. They were active in creating the Advisory Council and the Brain Injury Registry, and in gaining the recognition of brain injury as a separate disability in the Code of Iowa. They were also active in developing the Medicaid HCBS brain injury waiver. Iowa also has a number of cross disability groups that include people with brain injury in their advocacy efforts.

Are the services provided in a coordinated and family-centered manner?

In the every day lives of people with brain injury and their families, coordinated and family centered services are available sporadically, not as a system wide effort. This will become clearer in Section 5 on accessibility, where funding and eligibility issues and the unique delivery problems in this still very rural state will be explored.

Exploring the issue of coordination, the Hoyt-Mack telephone survey found that just under one-half of the respondents (48%) said that their service providers communicate effectively with each other. About one-fourth (24%) disagreed. The remainder had no opinion or does not get services from multiple providers. Some examples of comments were:

- Didn't work together at all
- Don't communicate with county- county doesn't give out resources
- Further away from immediate crisis the communication broke down
- JPTA and Voc Rehab wanted to do the same testing
- Therapist and PT each do own part, but really don't communicate with each other
- They don't talk to each other, are independent

When asked who is responsible for keeping all the different providers informed about what is going on, over one half (56%) of the survivors said it was themselves or a family member. About 20 percent named a case manager or social worker.

Are the existing services really for people with brain injury?

Like any part of the human service industry, services for people with brain injury will develop around funding. This is a serious issue in describing brain injury services in Iowa. Except for the recent Medicaid HCBS brain injury waiver, there are no designated funding streams for brain injury. The focus group on funding issues for this project discussed the problem of having people with brain injury served in a system set up for people with mental retardation and developmental disabilities.

As one provider said:

I think it's completely ignorant to have all our brain injury programming in the state of Iowa revolve around programming for people with mental retardation because that has been a mandated population by Iowa code that's been placed on the counties to fund. We have tried to gray every other definition and put them into existing mental retardation programming. Our chronically mentally ill get program-

ming for people with mental retardation too. It is totally inadequate.

Another provider noted:

What you have is every mom and pop nursing home saying 'I'll provide brain injury services'. We do a lot of work with South Dakota and it's fortunate for them now that they have somebody there saying 'No way, it ain't gonna' happen. It's not going to be mental retardation, it's not nursing homes, it's not mental illness. It's going to be for brain injury.'

While it is possible to identify resources in Iowa that fall under the service categories considered important for people with brain injury, it is also clear that the resources are often not there or are hidden and that after acute care, few programs are responding to the specific needs of people with brain injury. This is born out by the Hoyt-Mack provider survey, which shows TBI clients but few TBI targeted services.

In Section 5, we will explore the funding, program eligibility and geographic factors in Iowa that make accessibility of services a problem for many people with brain injury.

5. Is the array of services accessible to survivors and their families?

*You've put your finger right on the problem. This is what we experienced.
You run from one place to another one and no one is
responsible. It's always the other place.
Family Member*

*Everybody needs to get what they need because
they need it, not because they have a certain label.
Education Consultant for Brain Injury*

Section 4 explored whether the components of the service array for people with brain injury exist in Iowa. This section asks: Are survivors and their families eligible for those services? Can they pay for them? Can they get to them?

Funding, geography, and a historical lack of services to Iowans with brain injury all make accessibility a major problem for survivors and families. It is difficult to sort out the influence of eligibility, funding and geography. But both providers and consumers report that all of these factors seem to work together against easy access for survivors and their families.

In the telephone survey of consumers, the reasons given for *not* accessing needed services varied. Forty-two percent of the

consumers said the services were not available locally, and 35% said they didn't have the funds to pay for services. Sample comments from the survey show how the issues of eligibility, funding and geography blend together:

- Not available in area
- Maintaining improvements in range of motion not covered by insurance
- Not available in the area
- Didn't know what was available, school refused assistance
- Hard to find lots of activities for him to do
- They live outside of county line for bus transportation
- No real help in town she's in, and can't drive
- Don't provide to people over 21
- Doesn't know what available
- No money

- Cost and logistics of getting him to these places
- Transportation

A long time provider in a state agency summarized the situation at the focus group on funding:

I've worked with programs serving persons with disabilities and funding services for persons with disabilities for probably more than twenty years now. I've seen some developments and improvements in funding for some populations of persons. I would have to say frankly I haven't seen much improvement in the funding of services for persons with brain injury over that period of time. I think that the state and the county are basically passing the ball back and forth and neither is willing to say "Yep, it's my ball." I think people with brain injury are one of those populations that have been kind of ignored.

Iowa's Unique County System

Iowa is different from most states in the way it pays for services used by people with disabilities. Most of these services for adults (such as group homes and supported employment) are paid for with a combination of federal and county funds, not state funds as in other states. Iowa is first among all states in county contributions to services for adults with mental illness, mental retardation and developmental disabilities.

Figure 11

State contributions to community programs in Iowa: 1992

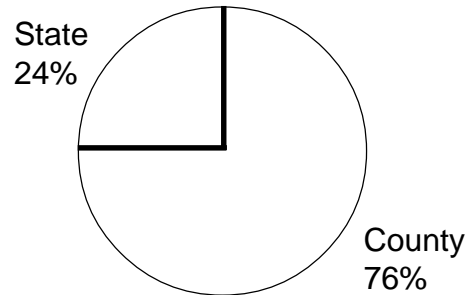
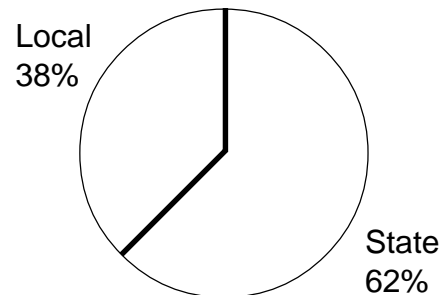


Figure 12

U.S. average state contributions to community programs: 1992



Iowa law requires counties to pay for services for people with mental retardation and for institutional services for people with mental illness. In fact, traditionally counties have paid for many more services. However, when budgets are limited, the first services to be cut out are those that counties pay for voluntarily, and this includes services for people with brain injury.

In the last ten years, county mental health services (which includes mental retardation and developmental disabilities) has assumed a larger and larger proportion of the county budgets, until it is now the second largest budget category. At the same time, a state property tax freeze has limited-growth in these county budgets.

Under recent legislation, each of Iowa's 99 counties is now required to submit an annual plan for who will be served and what services will be available to them. In the current plans, 24 counties specifically exclude people with traumatic brain injury from eligibility for services. Ten county plans "grandfather" in existing recipients with brain injury, but will not serve new consumers with brain injury. Nine counties include people with brain injury in their eligibility in some form, six through the new BI waiver. People who had their injury before age 22 may meet the developmental disabilities criteria for services in those counties where that population is included in the eligibility criteria.

The exclusion of people with brain injury from the eligibility for county funded services is part of the ongoing battle over state and county contributions to services. Many of the county plans specifically refer to the need for brain injury funding with phrases such as the following: *The county recognizes the needs of persons with brain injury. However, until the State of Iowa provides 100% funding to meet these needs, the county is unable to fund services for this population.*

The unbalanced pressure on county budgets to improve the scope and quality of services provided is well recognized. A county human

services coordinator provides a description:

Expectations of county funding are ludicrous. We don't have the money to meet the needs of the mandated categories we have now. One of my counties has the smallest mental health budget in the world, it's \$350,000. There's a young man we've become liable for who is severely disabled and his care is going to cost \$35,000 a year. That's 10% of our budget!

The variations in the county plans creates a complicated situation for survivors, when services vary from county to county and a move can mean lost services. It also causes complexities for providers, as described:

Being a provider, we serve people out of five different states in our facility right now. And I want to tell you that Iowa's definitely the toughest state to work with because of all the different county plans.

There are also those who feel that the local county control has the benefit of bringing decisions closer to home and making them more individualized. Especially in smaller counties, people with disabilities may know one of the three to five supervisors personally. Two county human services coordinators at the funding focus group agreed:

When we talk about people that suffer traumatic brain injury, we're not talking about a case file or a statistics. I'm talking about the person that I'm sitting with on the couch. I'm talking about the employee yesterday who asked for unscheduled leave to baby-sit for a family whose four-year-old was hospitalized for an inoperable brain tumor. It becomes so personal for us because this is our community.

There are a lot of inherent problems in having a system with as much flexibility as you have with 99 different county plans, but the feedback that we get from the community and our quality assurance measures say we're doing a good job.

The Medicaid HCBS brain injury waiver is currently the only funding available specifically for people with brain injury. The nonfederal match for persons 18 and over is the responsibility of the county of legal settlement; *IF* the county has designated slots for the brain injury waiver in their county management plan.

An added complexity in funding for people with brain injury in Iowa is the issue of the county of legal settlement. Medicaid funded services are determined by the county of legal settlement. If a person with a brain injury moves within Iowa, funding responsibilities stay with the original county of legal settlement. A person moving to Iowa after a brain injury does not have a county of legal settlement and becomes the responsibility of either the original state or becomes the responsibility of the state of Iowa. Conflicts over these responsibilities can turn the person with a brain injury who moves into a funding “hot potato,” adding to the problems of service access.

The conflict over state and county contributions is not the only “ball tossing” that affects service eligibility for people with brain injury. A family member says:

I mentioned the county and state handing the ball back and forth the person who is brain injured. But there is some of that between Medicaid and the schools too,

drawing a line between what is medical and what is educational. I think there are kids who fall through the cracks. Neither side is willing to pick up the whole ball.

An educator suggests a non-categorical approach to service eligibility:

The school system in Iowa no longer requires a child have a label in order to get services. We look at the needs that children have and try to match those needs with funding and what we can provide. I think if we can do it at the school level, we should be able to do it at the adult level as well.

Funding

In the case of some disabilities, there is often the argument that it is not the *amount* of money that is the issue in improving services, but the *efficient* use of funding— less duplication, more coordination. In the case of services to people with brain injury, this is not the case. The beginning issue seems to be fundamentally about quantity. “I guess I don’t want to give the impression that there is sufficient support, sufficient money, and its just being distributed inefficiently,” says one provider. “With brain injury, there is insufficient resources, first and foremost.”

The Life after Head Injury survey and the telephone survey both give a picture of the financial resources being used for services for people with brain injury. The Life After Head Injury survey showed some 15% of the respondents did not have health care coverage a year after their injury. Sixty-five percent reported having private health insurance and

only 11 % report being on Medicaid. Eleven percent reported being unable to see a doctor because of cost. This varied little across severity of disability.

In the telephone consumer survey, using a group averaging 10 years post injury, 16% of the respondents report SSI as being one of the services that they received. The majority of the services they report using were either free, such as the support groups, or provided with public funding (e.g., SSI disability). About 8 percent of the services are paid for solely with private insurance funds, and 6 percent are paid for with private funds. Approximately another 6 percent use sliding fee arrangements, with the survivor paying some portion along with either insurance or private funds.

The difference in responses between the Life After Head Injury survey and the telephone survey confirms comments about funding made in the funding focus group, namely that funding for immediate post injury services are often available, especially if private insurance is available. As one provider described in the focus group:

I think that somebody mentioned that there is probably a lot of money spent on a person with brain injury right up front, you know, at the time of the injury. Insurance companies, Medicaid. Everybody's dumping money into that. It's just that with brain injury, after that it just drops off like going over a cliff.

The funding focus group spent part of its time together outlining funding resources for the array of services identified for this project. The list, shown in Table 1 below seems substantial. However, the creators cautioned that it is deceptive. A provider looking at the list observed:

OK, we've probably got 20 things listed. Every single one of them has inadequate resources to provide the care. They all have their own guidelines that they have to meet, so imagine a 30-page application. Take something as simple as getting help for someone who needs to relearn how to cook a meal. We might have to access four or five of these funding sources, for transportation, some in home services. What if there were four life domains involved? We'd have sixteen funding sources and each one has a 30 page application. What do you think the chances are of that person ever learning to cook a meal?

It appears from this long list that there's a lot of money out there for brain injury, and there's not. It's a little bit in a few places. It is going to require a new source of funding and that's all there is to it.

Table 1: Sources of funding for service array for lowans with Brain Injury

(In some cases the agency/program is also the provicer of the service)

Developed by focus group on funding issues, June 16, 1998

	CHILDREN	ADULTS (over 21)	ELDERLY (over 65)
Medical Services			
	Medicaid/Title XI (Extensive for children, covers more than with adults); EPSDT.. no limits but income; self-pay private insurance; charity (hospital write-offs); family; county general assistance (Crisis)	Medicaid-Title XIX (but more restricted than for children); private insurance; self-pay; family; county general assistance	Medicaid; Medicare; Commission for the Blind; private insurance; self-pay; family; county general assistance; charity
Therapy (PT/OT/Speech)			
	AEAs if necessary for education; Medicaid; Medicare (rehab for period of time); Private insurance (usually underinsured for therapies); family; self-pay	Medicaid; private insurance; self-pay; family	Medicaid; Medicare; self-pay; family
Education			
	Public education mandated to 21 (many students/families don't know this and matriculate at 18)	DVRS can help pay for college for eligible client with plan and vocational goals; family; self-pay; private organization scholarships	

	CHILDREN	ADULTS (over 21)	ELDERLY (over 65)
In-home/residential			
	SSI/SSA (rigorous qualifications) Department of Public health Homemaker Health Aid grant (sliding scale); Family Support Subsidy (state program, waiting list); BI Waiver	SSI/SSA; county; County Care Facilities; homeless shelters; prisons; families; Home Health Aid grant; Personal Assistant Services model program (only a few counties; BI-Waiver; families; Mental Health Institutes	Area Agencies on Aging; Medicare
Transportation			
	School; families	Medicaid (for medical visits); charity; paratransit (county; families; self	Medicare; county transit; Area Agency on Aging; families; self
Independent Living			
		BI waiver; County; Voc Rehab; Independent Living Centers (Federal) United Way; charity	
Equipment and Assistive Technology			
	Some through education; BI waiver; charity (Lions); family; IPAT loans	BI waiver; Medicare, Medicaid; Independent Living Centers; charity; DVRS; PASS plans (DVRS); VA; county—(when there is no other funding), IPAT loans	

	CHILDREN	ADULTS (over 21)	ELDERLY (over 65)
Vocational			
	Schools to 21	Voc Rehab; VA; Dept. for the Blind; county; BI waiver; families; employers; PASS plans; IRWE	
Counseling			
	Schools	Community Mental Health; private ins (limits) Medicaid; BI Waiver; EAP; family; self	
Case Management			
	Fed/State Medicaid; BI Waiver; family	Fed/County; BI Waiver; family; self	Fed; Elder Affairs; family and friends
Advocacy			
	PE Connection; Brain Injury Association of Iowa; State Advisory Council on Head Injury; Dept. of Human Rights; DD Council; Iowa P and A; League of Human Dignity; ILC; Dept. of Public Health; DHS; family; friends	BI Waiver; Brain Injury association of Iowa; State Advisory Council on Head Injury; Dept. of Human Rights; DD Council; Iowa P and A; League of Human Dignity; ILC; Dept. of Public Health; DHS; family; friends; Voc Rehab	Area Agency on Aging

Geography

An individual's county of residence makes a difference in access to services because of the county funding system already discussed. In addition to limitations to service access imposed by the funding system structure, access to services is also impacted by problems associated with service provision in a rural state. Sixty percent of Iowans are living outside a metropolitan area, according to the 1992 census, making Iowa one of the top ten rural states. Iowa ranks 44th in the number of physicians per 100,000 population, a statistic that under-represents the scarcity of physicians in rural areas. On the other hand, Iowa is over the national average on number of motor vehicle accidents per mile traveled. In the TBIRDS review of rehabilitation facilities, 50% of the counties in the state had NO services identifying themselves as being for people with brain injury. In the telephone survey, consumers reported most of the services are accessed in the same community or within five miles of the survivor's home (75%). Another 12% say they go from 6 to 24 miles, 10 percent from 25 to 100 miles, and 3 percent travel more than 100 miles away. The longest distances are associated

with obtaining services at very specialized facilities. Having to drive at least moderate distances is more typical of rural residents. The difference between rural and urban populations in the time it takes to transport a crash victim with TBI to the hospital was covered in Section 1.

Summary

Issues of accessibility involve the connected issues of eligibility criteria, funding and geography. The relative weight of these factors is difficult to sort out, and they blend in turn with issues about the availability of services that are specifically designed for people with brain injury. As one provider explains:

You've got three issues as far as I'm concerned: You've got funding issues, you've got delivery issues, and you've got training and expertise issues. None of these issues are being addressed for Iowans with brain injury.

Section 6 will look at how Iowa survivors and their families have described their experiences with the service system, and their own views of unmet needs.

6.

Is the system meeting the needs of survivors and their families?

*It's hard to say what I need. Just more help. More options. More choices.
 –lowan with a brain injury*

*We need someone to help with all the problems that someone with a brain injury has, rather than just putting us aside.
 –Family member*

With eligibility, funding, and geographical problems all influencing accessibility to services for people with brain injury, it is no surprise that survivors and their families can identify unmet needs.

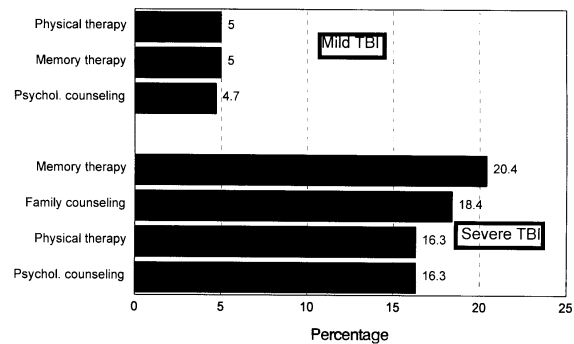
It is the strong consensus of survivors, family members and providers that after hospitalization and immediate rehabilitation, there is, for all practical purposes, no system of care.

Needed services

The Life After Head Injury (Schoutman, 1998) survey and the consumer telephone survey asked participants to identify services they felt they needed but could not get. In the Life After Head Injury survey, 22% of persons with traumatic brain injury indicated that they should have received services but did not. The most frequently mentioned services needed were physical therapy, psychological

counseling and family counseling. Sixteen percent of those who sustained mild traumatic brain injury stated that more services were needed while 42.8 percent of those with severe traumatic brain injury reported needing more services. The top three services named by those who sustained mild traumatic brain injury were physical therapy, memory therapy and psychological counseling. Memory therapy was the most frequently

Figure 13 Services that should have been received but were not by injury severity*



* Persons with moderate TBIs not included due to small sample size

mentioned service needed for those with severe brain injury. Family counseling, physical therapy, and psychological counseling were also mentioned frequently.

In the telephone interviews, which consisted of more long term survivors, a little over two-thirds (68%) of the survivors indicated that there were services that they needed but were not getting. Thirty-six percent of the needed services identified were supports for community living, including transportation. Over half the responses in this community living category were needs for recreation and social opportunities for people with brain injury, not the more traditional supported living services. Respite services for families made up about 20 percent of this group as well. Sample comments from the survey include:

- Someone to help in the house. It's just too much for one person
- We need transportation. We're 2 and a half miles outside Woodbury county where his other services are and he can't get bus services to our home
- I need a social life, somewhere to go
- Need activities and social opportunities
- Organized recreational opportunities
- The family has all the burden. Need a break once in a while
- Need a life outside of medical stuff

Therapies, including occupational therapy, physical therapy, speech therapy and counseling services each made up 15% of the identified needed services. Specific services mentioned included:

- Psych services and counseling for family
- Stress management. Anything out of the norm is stressful

- Psychiatric help
- Physical therapy, at least 1 time per week
- Private pay speech

The Brain Injury Association of Iowa recently did a survey (BIA-IA, 1998) of their membership. One of the questions involved identifying their top needs, as survivors or family members. Of the 59 respondents, 23% put counseling down as one of their top three needs, 20% included community living topics in their top needs. Training was also identified as a need by 20%. Educational issues followed with 16%. Sample responses included:

- Services to get survivors back into community living post intensive care
- Additional services in the community.
- A person to talk with
- Training—families don't fully understand the characteristics of people with brain injury
- Increasing funds available for education and associates in schools to assist students with brain injuries

A recent study (Deason, 1994) looked at the relationship between family stress and the lack of services for persons with brain injury in central Iowa. In telephone interviews with 45 family members, twenty percent felt they did not have good support from the Department of Human Services in their management of their family member with brain injury, while 53% were undecided. Regarding residential services, 86% strongly agreed that there needed to be more residential options. Ninety-three percent felt there needed to be more vocational services, and 92% felt there needed to be more social activities. About half of the survivors were at home during the day and the other half were not. Deason's work showed that this factor alone did not

account for stress reported in a family's life. Deason work also showed that three times as many of the caretakers were women as were men.

Information and Referral

The telephone survey asked specific questions about information and referral services. One person interviewed referred to information and referral as "help finding out what help we can get." Just over one-half (53%) of the respondents reported having trouble getting information about where to get services or help: not knowing where to begin looking, lack of coordination, lack of knowledge about services among providers, and lack of post-hospital information. Some examples of responses:

- When first injured, neurologist was not very knowledgeable about services
- Frustrated early on trying to work with the system and bureaucracy
- Services for TBIs are not coordinated
- Head-injury association send out newsletter, but is not services or resource oriented
- Would have been easier if she were a child
- Not a lot of services locally, information about services stopped when left the hospital
- Does not know where to look into services for certain needs
- No center for information
- No one contacted them after accident
- Different people gave different recommendations, hard to know where to go
- Has no idea of who to turn to

- In the beginning was worse, few things available
- Had no idea where to look
- Information from the hospital was too soon, family was overwhelmed

Training

While training in brain injury is not always a service directed to families and survivors, it surfaces repeatedly throughout this report as one of the keys to improving Iowa's service system: There is an overall lack of service providers with an understanding and specific expertise in working with individuals with brain injury. The providers surveyed by telephone typically noted that their services were not specifically targeted to survivors of traumatic brain injury. In effect, many offer services that persons with TBI need but don't have specialized knowledge of issues such as the coordination of services for survivors.

As part of this project, the Iowa University Affiliated Program conducted a postcard survey to identify the most needed training topics. Over 100 professionals responded to the survey. The mailing list consisted of a variety of professionals involved with students with brain injury, including school nurses and the Area Education Resource teams. Sixty percent of the respondents included behavior issues in brain injury as one of their top three topics. Educational strategies for students with brain injury was named by 42% of the survey respondents. About 30% of the respondents included visual/perceptual problems in brain injury, family issues and concussions in sports.

The Iowa Department of Education's consultant on brain injury recently surveyed the fifteen Area Education Brain Injury teams in Iowa. They were asked about training needs for the teams specifically, and then also about needs for the classroom teachers and para-educators who will be working with students with brain injury. The AEAs reported some of the following needs:

For the teams:

- A packet or training package for educators that we could use when we inservice teachers
- Yearly update of skills and contact with experts in the field
- Information on new meds for immediate post- injury
- Suggestions for evaluating students for placement
- When kids have been in services for several years, we need maintenance support for families and teachers who see little improvement in the kids
- More information on home services for families and financial services, and counseling for families
- Continuing need for functional assessment for BI kids
- Medical concerns on reentry.
- Preparing for reentry

For general education teachers:

- More information on how these students differ from typical LD or MD
- More training on how to implement modifications in school
- Overview of teaching strategies and behavior management
- Video of basic information needed...

- Training isn't useful without a specific student in the classroom...the information wouldn't generalize
- Training on functional behavior analysis
- Basics on brain injury
- 504 accommodations and brain injury
- Managing students with brain injury in regular ed classroom
- How to tell brain injury related behavior from age normal behavior

The survey also asked the teams to assess how well the schools are meeting the needs of students with re-entry into schools:

- The teams themselves are a strength in terms of education's response
- The teams have helped teachers be willing to accept the students back into the schools, because they won't be alone
- There is a good relationship between hospital rehabilitation and the brain injury teams
- Non labeling means we can have a flexible approach and mix general ed with special ed

The survey also asked about how the AEAs can better meet the needs of families:

- There is nothing written in an IEP as to how parents and or families will receive support. Should there be? And if so how? What services or supports should be suggested to families?
- If parents do not want help, but it is clear that help is needed for the student with a brain injury to progress, what should be done?
- Do we have any role with students who have a brain injured parent or sibling?
- We need more time for follow up with families

- Find a way to make sure families know about brain injury teams before the child leaves the hospital
- It would be good to have special training in how to help families
- We should have support groups for both students with brain injuries, and also the parents of the students with brain injuries

Best and Worst Experiences

While specific unmet needs and system wide needs have both been identified here, it is important to note that positive experiences with services are also part of the lives of survivors and their families. In the telephone survey, nearly all of the respondents (92%) could name a positive experience with some service. The comments provided often focus on comments about a particular provider or program that made a difference. Some examples follow:

- The resource room and the special education teachers—it is 1 on 1
- Occupational therapist was very helpful and gave us good tips for practical daily activities
- Agency provided companionship and help with some tasks of daily living (but was grant funded and got cut)
- Vocational Rehabilitation, they offered to help when others would not
- Evaluation by neuropsychologist was very helpful in letting them know what their situation was
- Medicare has paid bills
- Speech therapists, very knowledgeable about injury and have given family the most encouragement

- County supervisors were very willing to do what they could
- The kindness of people

Three-fourths (75%) of the respondents in the Hoyt-Mack telephone survey could also identify a “worst” service experience. Just as the best experiences were very individualized, so were the worst experiences. Indeed, it is interesting to note that some of the same services, or types of services, appear on both lists. Some examples of the worst experiences refer to the eligibility and funding issues that have been covered in other sections:

- Fell through the cracks in the beginning, had to pay all of the bills
- Program failed to follow through with promises, kicked out when behavioral problems, rather than working on them
- Waited for over 2 years for Title 19 bed for brain injured program in ICF
- No speech or physical therapy in ICF
- As soon as insurance ran out, people less willing to help
- Trouble with respite care, difficult to get SSI – took 10 years. Penalized because a housewife which did not count as employment
- No follow-up after hospitalization
- Insurance company is horrible to deal with
- Bad experience in rehabilitation program, went in sociable, came out withdrawn
- Lack of local services
- Some doctors closed-minded, treat as textbook case
- Did not find out about social security services until had used all of personal savings
- No one her age in nursing homes
- Had to leave state to get needed services

- Funding will not let her move to facility for disabled persons
- Have been told to get a divorce, in order to qualify for more funding
- Early, problems were not recognized as TBI, treated for mental health problems
- Left hospital thinking things would be fine, then no referrals
- Some providers are condescending

Summary

In its conclusion, the telephone surveyors asked consumers to add any additional comments about the service system. It is easy to find the unmet needs in these statements.

On the array of services:

- Treatment needs to be available throughout the process, don't just need help right when it happens, but when other changes occur..
- No attendant care in the area. This is a concern when family may no longer be able to meet the care needs
- Worried about care once parents can no longer provide it..
- More counseling services, especially marital counseling for spouses of TBI

Information and referral:

- Need someone in hospital to explain what is going on and what is available

Training:

- Sometimes wish he had something physically wrong so others would understand him better
- At the time of injury, professionals did not seem well-informed

Funding:

- Main problem financing. Iowa declined because accident happened in another state. Other state refused because he was no longer a resident
- There should be more funding for TBI patients because it is not like just getting over an operation, it is a lifetime ordeal
- Hard to get services for people over age 21

The big systems issues in services appear in the every day lives of survivors and families as many small absences and frustrations. The strongest unmet needs and frustrations are not seen in the immediate crisis and recovery after a brain injury. It is in the post-acute period that survivors and families feel the absence of a system. Therapy, counseling, and supports for community living could offer concrete assistance and relief from the isolation and responsibility that many families and survivors experience.

Section 7 will offer a summary of the issues that have been identified in the needs assessment and the first state plan for addressing these needs.

7.

What can be done to improve Iowa services and supports for people with brain injury and their families? The Iowa Plan for Brain Injury

Some things occur to us in life and they occur suddenly, and we don't have any transition time. We don't have any preparation. Brain injury is one of those things. And then people have to make a connection between their life before the injury and after the injury.
—Brain injury consultant

In college it was great, because it seemed like... It didn't seem like they were your teacher anymore, they were more your friend. They were trying to learn as much as you because they didn't understand brain injury, and I didn't understand the material. Everybody worked together. I got my degree in retail and now I have a job.
—Iowan with a brain injury

The Iowa Plan for Brain Injury, developed by The State Plan Task Force of the Iowa Council on Head Injuries, is Iowa's first official answer to this section's question.

People with brain injury have been referred to as an emerging population. It is emerging because the capacity to save people with head trauma has improved dramatically. The needs of people with brain injury cannot be met through the established mental health or mental retardation approach to services.

The needs assessment has identified ways that this systemic service problem can be addressed. The major points that have emerged in the previous sections relate to family needs for services and supports, eligibility requirements, funding issues, and training needs. But a new service system has not yet developed specifically for them. Thus, they are usually served inappropriately or not at all.

The priorities identified by the State Plan Task Force follow.

Families

In the absence of a strong service system for people with brain injury, families are the primary service providers in Iowa today. Even with a more developed service system, this would be true, as it is for other people with disabilities, including the frail elderly. The moral imperative of strengthening and supporting families in this difficult work is also a cost-effective approach to services. Families and survivors are asking specifically for therapy and counseling, information and referral services and a varied array of help for community living. In the bigger sense, what they are asking for is not to be left alone in their responsibilities.

Funding

Some argue that everything is about money. There is general agreement that people with brain injury need access to more service funding. However, various groups with needs compete for available funding from the government. To develop an accessible array of services for people with brain injuries, a combination of private, state, and federal, funds need to be used.

There is general agreement that the county system of funding adult services must be changed, with the state taking over more responsibility for that funding. Others have suggested some new funding could come from a "sin tax" on people arrested for drunk driving, speeding, or not wearing a seat belt. Since such a high proportion of traumatic brain injury occurs as a result of motor ve-

hicle crashes, this would be a reasonable source for those funds.

Eligibility criteria for services for people with traumatic brain injury include, but are not limited to, the following: the age of the person applying for services, their age when the disability was incurred, diagnosis, degree of disability, income, family income, county of residence, state of residence, and access to insurance. For families, it may seem at times that eligibility is just a lot of different ways to get a no, a different one at every agency or source of funding.

Training

Increasing Iowa's resource of providers who are knowledgeable and experienced in the area of brain injury is as important to service improvement as the funding. There is acknowledgement of this across agencies and disciplines, as well as with the survivors and families. Training needs to cover the spectrum, from general information about brain injury, its causes and consequences, to technical disciplinary training.

Information and Referral

The need for information and direction to resources is critically lacking, for survivors, their family members and providers. Beginning at the hospital, the family needs to know where to turn for help and how to access the currently limited services and funding that are available.

Case Management/ Service Coordination

Case management services that are not simply finance management and gatekeeping were seen as a critical need for survivors and their families. Currently only available in a limited way for people with brain injury, this area was seen as a key to life planning for maximum level of rehabilitation and independence.

Transportation

In this rural state, transportation is seen as a critical element in accessing all other services and in maintaining the maximum independence possible. While a few urban areas have fully developed transit systems, much of the state depends on a relatively sparse and inflexible system of public transit.

Housing

Access to a range of supported housing options, from total independence to age appropriate community based supervised living, has been identified as a serious missing link for people with brain injury. There are few options for an adult with a brain injury, between nursing home care and living with the family.

Employment

A range of support services related to employment have come of age for people with other kinds of disabilities. But the system is not yet responding effectively to the unique needs of adults with brain injuries who need help in accessing and maintaining employment.

THE PLAN

With these areas of focus in mind, the State Plan Task Force spent two days together outlining a response for Iowa in addressing these concerns. The task force developed the following areas of special focus.

AREA 1

Increase funding for persons with brain injury across the continuum of care.

Rationale: The needs assessment clearly indicates that funding that people with brain injury are able to access is practically nonexistent. Public understanding of this disability was seen as the starting point for funding advocacy.

Year 1

- Promote recognition of brain injury as a disability
 - Increase media coverage
 - Agree on a single definition of brain injury
- Gather, compile, and agree on the interpretation of baseline data
- Decide what we are requesting
 - Define a model system
 - Decide on a core set of services for model system
 - Assign a dollar amount on a core set of services
- Develop source of funding for long-term services and identify legislative processes for implementing the system
 - Review and agree upon model system of care
 - Coordinate with Brain Injury

Association and other interested groups and reach agreement

Other suggestions from the Task Force

- Examine the possibility of target funding based on prevalence
- Fund services linking with standard of care levels
- Review availability of funding from third-party payers
- Review utilization of e-codes for data collection and tracking purposes
- Investigate decategorization with funding based on functional definitions
- Consider prevention of secondary conditions

AREA 2

Develop and implement standards of care to ensure quality and cost effectiveness and linkage to funding for care.

Rationale: It was felt by the task force that the need to upgrade the level of response through training would have to first be met by identifying the standards that caregivers need to have.

Year 1

- Begin survey and compile data on service utilization in the state of Iowa
- Survey range of standards of care available, including those of accrediting bodies
- Explore the potential for deemed status and develop a time line for introducing into the legislative process (Council approval by July, 1999)

Year 2

- Recommend standards of care for acute, postacute, and community levels

- Introduce recommendations for standards of care into legislative process

Other suggestion by the Task Force

- Associate funding with standards of care level and coordinate funding initiative activities with legislative initiatives for establishing standards of care

AREA 3

Develop and implement training for service providers and families.

Rationale: Training was identified as a critical element in developing services that are truly directed at the needs of people with brain injury.

Year 1

- Expand training surveys where necessary
- Establish a state advisory committee on brain injury training
- Identify all current training by topic, locale and target audience
- Consider joint conferences across disciplines

Year 2

- Centralize training resources (i.e., videotapes) for distribution/sale/checkout

Year 3

- Develop an ongoing, comprehensive plan for brain injury training
- Train on standards of care

AREA 4

Make case management available to all people with brain injury.

Rationale: Case management services were

seen as essential to well-coordinated and cost-effective services.

Year 1

- Research range of models for case management/service coordination, including those used by different states
- Review different models of case management
- Recommend a model of case management/service coordination for Iowa
- Increase support for families/caregivers to augment the limited model recommended

Year 2

- Assign a cost to the model recommended
- Define outcomes for case management/service coordination

AREA 5

Develop and implement a single point of contact for statewide information/referral services.

Rationale: Across all components of the needs assessment, information and referral was identified as a major need.

Year 1

- Develop or bolster a central point of information (CPI)
- Develop a website for CPI

Year 2

- Link to local first points of contact
- Increase media regarding the availability of CPI
- Revisit and revise initial and follow-up information packets for support and

intervention in the acute, postacute, and community levels of care

Year 3

- Determine the costs of both the minimum and ideal level of CPI
- Build a network of local brain injury contacts and experts

AREA 6

Develop and implement access to life care planning services.

Rationale: Life care planning, when consistently utilized, can improve quality of life and reduce costs.

Action steps:

- Study models for care planning utilized by the insurance industry as well as those used by other states (particularly adjoining states)
- Develop pre-discharge model for use beginning with acute care settings

AREA 7

Develop and implement community supports for persons with brain injury.

Rationale: Community supports, including transportation, housing and employment services, were identified as being almost nonexistent. Plans for these elements will be identified in the future, based on the standards of care developed.

The Advisory Council on Head Injuries is developing specific action steps for this area.

Moving Forward

The implementation of this plan will be an ambitious undertaking but one that is long overdue. The Iowa Department of Public Health's successful application for a second year of funding from Maternal and Child Health will provide a boost to these start up efforts. It will, however, be Iowans with brain injuries, their dedicated families and caregivers who will provide the energy to move forward.

REFERENCES

Brain Injury Association of Iowa, Unpublished Member Survey, 1998.

De Boer, Paul, State Agency Report, Unpublished report, Iowa Department of Public Health, Des Moines, 1998.

Deason, Dwight, Stress and Lack of Services for Persons with Brain Injury and Their Families in Iowa, Unpublished research report, 1994.

Fick and Petty, Statistics on Brain Injury, Neurolaw. Com/brain.html 1997

Hoyt-Mack Research Associates, Report on survey of survivors of brain injury, and providers of brain injury services. Ames IA, 1998.

Iowa University Affiliated Program, Unpublished transcript. Focus group on Funding of Services for People with Brain Injury, June 16, 1998.

Kraus, J. and McArthur, D. Epidemiologic aspects of brain injury. *Neuroepidemiology*, Vol. 14, number 2. 435-450, 1996.

McMordie, W.R., Barker, SL and Paolo, T.M. Return to work (RTW) after head injury. Brain Injury, Vol 4. No 1., 57-69, 1990.

Ragnarrson, K., Thomas, J., Zazler, N. Model systems of care for individuals with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, June 1993.,

Schootman, M. and Harlan "Severe Traumatic Brain Injuries in Iowa 1994" Report from Iowa Dept. of Public Health, Des Moines, 1996.

Schootman M. and Harlan, M. "Traumatic Brain Injuries in Iowa 1995" Report from Iowa Dept. of Public Health, Des Moines, 1997.

Schootman M., and Harlan, M. "Traumatic Brain Injuries in Iowa 1996." Report from Iowa Dept. of Public Health, Des Moines, 1998.

Schootman, M. Report on Life After Head Injury: A Questionnaire, Iowa Dept. of Public Health, Des Moines, 1998.

Stephan, James, and Memola, Christopher, "State and Federal Corrections Facilities" Correctional Populations in the United States, Bureau of Criminal Statistics, 1997.

Traumatic Brain Injury Rehabilitation Survey (TBIRDS), Funded by The University of Iowa Head Injury Prevention Research Center, Iowa Dept. of Public Health and the Governor's Advisory Council on Head Injuries, Des Moines., February 1997.

United States Census Bureau, 1990 U.S. Census, Washington D.C.

United States General Accounting Office, Traumatic Brain Injury Programs Supporting Long Term Services in Selected States. Report to Congressional Requesters. February 1998.

University of Iowa Injury Prevention Research Center, Iowa Dept of Public Health and Governor's Advisory Council on Head Injuries, Traumatic Brain Injury Rehabilitation Survey, Des Moines, 1997.